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This study accessed the firsthand perspectives of persons with Alzheimer's in order to report their friendship patterns with cognitively intact friends. I expected to find a gradual breakdown of respondents' networks and negative processes to characterize their friendships. The initial goal was to interview 15 Caucasian women in the early-stages of Alzheimer's about a friendship with a good friend. It was difficult to recruit the target sample size because of the ambiguities of the diagnostic process combined with the protection of the population. The final sample size was four with the findings supporting the idea that both personalities and previous patterns of relating carry into the disease experience. Alzheimer's disease is not always associated with a friendship network breakdown. Persons with Alzheimer's can still remain engaged in fulfilling friendships following their diagnosis that do not have to be characterized by negative processes. This population can also successfully inform research by participating in interviews. This study provided two outcomes, with the methodological one focusing on how to sample the population and the substantive one examining the originally intended topic of the friendships of persons with Alzheimer's.

‘REACT AND GO WITH IT’: INTERVIEWING PERSONS
WITH ALZHEIMER’S DISEASE ABOUT
THEIR FRIENDSHIPS

by

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Committee Chair

To all those living with Alzheimer's disease or another dementia. May you be treated with dignity and may your voice be heard. Your voice is necessary for the rest of us to understand what you are experiencing.

APPROVAL PAGE

This thesis has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

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CHAPTER I

INTRODUCTION

Purpose and Intent

The prevalence of Alzheimer's disease has steadily risen with the graying of the U.S. population. Every 72 seconds a new person develops the disease, continually adding to the five million individuals already living with it in the United States (Alzheimer's Association, 2007). Clearly Alzheimer's disease is a topic worth studying. On another note, the friendships of older adults are as well. They are an important part of older adults' lives and are a critical component in their well-being. For people with Alzheimer's disease, friendships might be of even greater significance. Because of the heightened prevalence of this disease, researchers need to take interest in all matters regarding the person with Alzheimer's, including such a seemingly superfluous topic as friendship.

Throughout the past, the research on Alzheimer's has centered on the biological aspects of the disease with researchers often ignoring the social lives of the individuals who are diagnosed with it (Jaffe & Miller, 1994). A biomedical model has dominated the research literature, with the social experiences of persons with Alzheimer's receiving minimal attention. Studies that do actually concentrate on the social relationships of persons with Alzheimer's primarily examine familial or caregiving relationships, with friendship relations occupying minimal concern.

Not only have researchers overlooked the social experiences of the person with Alzheimer's, but they have also pushed these individuals' perspectives to the side as well (Cotrell & Schulz, 1993). In past research, scholars have often failed to include the perspectives of persons with Alzheimer's disease, demonstrating a clear bias toward the caregiver's viewpoint. Essentially, the friendships of persons with Alzheimer's as well as their firsthand perspectives have received passing attention in the research literature.

In an effort to move toward obtaining firsthand accounts of the social experiences of persons with Alzheimer's disease, the focus of this study was on the friendships between persons with Alzheimer's disease and cognitively intact individuals as described by the person with Alzheimer's. For the purposes of this paper, I defined this particular kind of relationship as a mixed friendship. This study brought together two primary areas of research (studies on the firsthand perspectives of persons with Alzheimer's disease and the literature on older adult friendship) in order to examine the friendship patterns of persons with this disease.

In the present study, I used the concepts of interactive processes (what takes place within friendships), internal structures (the form of the ties linking friends together), and friendship phases (the evolution and change friendships undergo) to frame the research (Blieszner & Adams, 1992). The primary question of this study was: what are the patterns that characterize mixed friendships? That is, what are the interactive processes, internal structures, and friendship phases that characterize these relationships? I did not formally test any hypotheses in the present study but instead considered it to be a

hypothesis generating study intended to guide future research on the topic of mixed friendships.

This qualitative study accessed the perspectives of individuals with Alzheimer's via in-depth, semi-structured, face-to-face conversations using an interview guide in a similar fashion to Sarah Matthews (1986) in her study on older adult friendship. I initially set out to report on the perspectives of 15 Caucasian, community-dwelling women with Alzheimer's disease who were able to provide informed consent. It proved to be very difficult to recruit respondents, however, so I completed interviews with only four women. For the participants I did recruit, I asked them to report on a friendship with an individual they would describe as a "good friend." My purpose in doing so was to chart the patterns that occurred in their friendship with a cognitively intact individual after they had been diagnosed with Alzheimer's disease.

The research providing the backdrop for this study showed evidence of the gradual deterioration of friendships for the person with Alzheimer's. I expected these relationships to deteriorate due to the stressors associated with the disease and believed that I would find a breakdown in the friendship networks of the person with Alzheimer's. I also thought that I would find a host of negative patterns within the friendships that actually survived the individual's diagnosis.

As previously mentioned, I did not recruit the originally intended number of participants for this study. After beginning to collect data for the study, it was unyielding to proceed with the original research guidelines. Chapter three provides an in-depth report of the situations I encountered while recruiting participants. This study essentially

had dual outcomes, one methodological, relating to the nature of conducting studies accessing the firsthand perspectives of this population, and the other substantive, relating to the friendships of persons with Alzheimer's disease. Regarding the methodology of this thesis, I found that it is difficult to survey this population because of the largely protective, yet sometimes constraining ethical guidelines that researchers must abide by, the various gatekeepers that researchers invariably have to encounter, and because of an overall lack of unorthodox methods necessary for interviewing such a population. More aptly stated, researching this population is not a simple thing to do. Regarding the substantive part of this thesis, I found that persons with Alzheimer's bring their personalities and pre-Alzheimer's ways of relating to friends into the disease, that there are various factors that facilitate and constrain the person with Alzheimer's friendships and that in some cases, the friendship network of the person with Alzheimer's does shrink.

The Reporting of the Present Study

Essentially, the present study yielded two theses. The first thesis is methodological in nature, focusing on how to conduct research while accessing the firsthand perspectives of persons with Alzheimer's. The first half of this paper provides a review of the literature on the topic, how I actually carried out the present study, and a summary of the methodological situations I encountered while engaged in the process and a set of specific guidelines for other researchers interested in the topic. The second part of this paper is substantive in nature and focuses on the friendships of persons with Alzheimer's disease. As with the first thesis, this one is composed of three chapters: a

review of the relevant literature, what I discovered upon collecting the data, and a discussion of my findings on mixed friendship patterns. The last part of this paper unites the two theses in an overall discussion on conducting studies on mixed friendship patterns while interviewing persons with Alzheimer's and ends with a set of final conclusions from the study.

CHAPTER II

METHODOLOGICAL LITERATURE REVIEW

Introduction

This chapter provides those researching persons with Alzheimer's a general framework for use in studying Alzheimer's populations. The primary audience for which this chapter is intended is scholars who are interested in accessing this population's perspective. The chapter begins with the necessity for researchers to pursue these perspectives firsthand and then addresses qualitative methods generally appropriate for doing so. From this point, it focuses on the topic of Institutional Review Boards (IRBs), outlines the need for informed consent in research studies, and illustrates the types of situations researchers of persons with Alzheimer's can expect to face regarding the informed consent process. After providing an in-depth look at consent issues with this population, the chapter illustrates examples of the roles professional and family gatekeepers play in such research. The chapter concludes with a discussion of interviewing persons with Alzheimer's. The purpose of this chapter as well as the following one is to help generate more studies on the perspectives of persons with Alzheimer's disease.

The Necessity for Firsthand Accounts

Until recently, researchers have focused primarily on the biomedical model of Alzheimer's disease, with the majority of attention being given to the symptoms and the link between brain functioning and cognitive and behavioral processes (Cowdell, 2008). As a result, scholars have largely failed to account for the social and contextual factors influencing the person with Alzheimer's, seemingly ignoring the lived experiences of these individuals (Cowdell, 2008; Jaffe & Miller, 1994; MacQuarrie, 2005). Even social scientists have not adequately addressed the topic of Alzheimer's disease, as Jaffe & Miller (1994) explain:

We have many studies of services and their delivery systems as they relate to Alzheimer's disease, and we have many descriptions of various methods of testing memory, speech, and other cognitive processes. But the individual with the disease and his or her lived experience is conspicuously absent. This promotes a view of the person with Alzheimer's as a lifeless form with major cognitive and social deficits, the cause of overly stressed caregivers and strained service-delivery systems. (p. 59)

To date, there is a tension between the medical and social models in the research conducted on this disease. Researchers cannot ignore the fact that there is a pathological process to be studied; however, they need to balance that against the fact that the individuals they are studying are more than a disease. The tendency to rely on the biomedical stance robs researchers of focusing on the individuals they are attempting to study (Goldsmith, 1996).

Not only has a biomedical model dominated the research on Alzheimer's disease, but a focus on the caregiver's perspective has as well, with relatively few studies being

centered on the individual with Alzheimer's perspective. In the non-biomedical studies of Alzheimer's, there has been an overall trend for scholars to place primary attention and value on the caregiver rather than on the care-recipient's experience (Jaffe & Miller, 1994). Essentially, the perspective of the person with Alzheimer's is often non-existent and is largely excluded from the research (Dewing, 2002; Wilkinson, 2002). This was perhaps most clearly evident in the mid-nineties when the majority of gerontological inquiry was on topic of caregiving (Jaffe & Miller, 1994). Persons with Alzheimer's are still largely overlooked (Gillies, 2000), as researchers continue to use caregivers as primary informants. "The person with dementia thus finds her or himself at best marginalized and sometimes made invisible, as apparent by the dearth of subjective accounts in an otherwise vast literature" (Gillies, 2000, p. 366). This clear trend to pursue the caregivers' perspectives in the majority of studies has silenced the elderly, ironically resulting in quite a distance between the researcher and the actual population of interest, persons with Alzheimer's.

Although the caregiver's perspective is a vital contribution to the knowledge base on this disease, the experience of the person with Alzheimer's cannot be completely or adequately obtained from a proxy report (Wilkinson, 2002). After all, who knows better what it is like to have the disease than a person with the disease (Robinson, 2002)? When scholars focus solely on the caregivers' stance, valuing their perspectives of the disease experience over that of the person with Alzheimer's, they are not only missing out on an exciting vantage point but are also disempowering the person with Alzheimer's by maintaining the status quo voices of authority, these voices being theirs (as researchers)

and the caregiver's (Jaffe & Miller, 1994). By failing to include persons with Alzheimer's as participants in research, they are fostering stigmatization and social isolation for these individuals, as well as depriving future generations of knowledge (Loue, 2004). Not only do scholars need to examine the position of this population in the research (Wilkinson, 2002), but they also must maintain the attitude that persons with Alzheimer's are *the* expert when it comes to what they are experiencing. The scholarly community can begin to demonstrate this attitude by mandating the inclusion of individuals with Alzheimer's in research studies, rather than solely relying on proxy accounts of the disease experience.

A portion of the research literature's relative lack of firsthand accounts of the disease experience (Wilkinson, 2002) results from the perceived (and often actual) challenges to verbal communication and understanding for the person with Alzheimer's (Corner, 2002). Few people take time to listen to the voice of this population firsthand as they believe that individuals with Alzheimer's are unable to express themselves and reflect on their personal situation (Goldsmith, 1996). Scholars, professionals in the aging industry, and the lay public alike routinely believe persons with Alzheimer's are unable to participate in research because of their cognitive impairment, often subscribing to the stereotype that they are unable to communicate (Yale, 1999). "Assuming that people with dementia cannot participate in research or are unable to share views and experiences is a reinforcement of negative stereotypes of incapacity" (Wilkinson, 2002, p. 10). The misconception that they cannot participate in research is based on generalizing the late

stages of Alzheimer's disease to the entire population. Indeed, persons with Alzheimer's display great variation in abilities.

Contrary to commonly held assumptions, a person with Alzheimer's can participate in interviews (Gwyther, 1997), and his or her cognitive decline should not be the basis of exclusion from participation. Although Alzheimer's disease clearly does involve communication problems, changes in memory and in perception, researchers should not deem the person's contribution as invalid or unreliable (Gillies, 2000). More so than focusing on the reliability of what the person is saying, researchers should instead turn their attention to how to find the meaning and interpretation behind it (Dewing, 2002). As Goldsmith (1996) aptly states:

It is not acceptable at an early stage, nor even at a later stage for that matter, to write off a person's ability to communicate just because we find it difficult to comprehend what they are trying to convey to us. If there is a problem in understanding, then the responsibility lies with us to ensure that we are doing everything possible to facilitate communication. (p. 52)

Scholars' methodologies, rather than the person with Alzheimer's ability to communicate, can be barriers to moving toward the inclusion of these individuals in research (Pratt, 2002).

Not only do persons with Alzheimer's demonstrate the ability to participate in research, but they also express the desire to do so as well; many, however simply lack the opportunity (Cotrell & Schulz, 1993; Yale, 1999). Members of this population are often pleased to be involved in research, as it can fulfill the desire to be part of something and the urge to feel useful (Gwyther, 1997), along with needs for activity, attention, and

socializing (Corner, 2002). One woman with Alzheimer's spoke of her research involvement as making her feel worthwhile (Robinson, 2002). Although their research participation might not help their present situation, individuals in the early-stages have reported feeling good about at least helping their grandchildren's future (Gwyther, 1997).

For the academic, professional and lay communities to help increase the quality of life for these individuals and to possess some level of understanding of the experience of this population, it is absolutely necessary for researchers to pursue their firsthand perspectives (Wilkinson, 2002). As previously illustrated, people with Alzheimer's can provide a significant contribution to research (Corner, 2002) and hearing their voice is crucial to the creation of knowledge on the disease (Gillies, 2000). Not only does obtaining the firsthand accounts of people with Alzheimer's strengthen the quality of the data, but the individual interviewed also has "the opportunity to be the center of another's attention, to tell one's unique and unheard story, to engage in the process of self-scrutiny, and to experience catharsis" (Cotrell & Schulz, 1993, p. 208).

Fortunately the research community has taken notice of the exclusion of the person with Alzheimer's experience from the existing literature and there has been a shift within the past decade with scholars starting to consider these individuals as key actors in the research process. As of the early 1990's, accessing the views of this population was novel, as researchers, especially in the United Kingdom, were attempting to identify practical ways of doing so (Goldsmith, 1996). Researchers have paid increasing attention to the person with Alzheimer's experience and as a result, the literature documenting these perspectives is growing (Clare, 2003; Cowdell, 2008; Dewing, 2002; Gillies, 2000;

Pearce, Clare, & Pistrang, 2002; Pratt, 2002). Researchers such as Kitwood (1997), Phinney (1998) and Clare (2002; 2003), among others (i.e., Bartlett & Martin, 2002; Gillies, 2000) have helped establish this trend by conducting studies accessing the firsthand accounts of the population. There are also research organizations such as the Bradford Dementia Group who place the person with Alzheimer's or other dementia of primary value (Clarke & Keady, 2002) and grant programs such as Quality Research in Dementia that involve these individuals in shaping the research (Corner, 2002). As greater numbers of persons with Alzheimer's are diagnosed earlier, the research community will need to focus on their perspectives even more (Gwyther, 1997).

I conclude this section with a quote by Cotrell & Schulz (1993) that precisely illustrates the lack of, yet the need for firsthand accounts in Alzheimer's research:

Rarely is the afflicted individual viewed as a contributor whose perspective is essential to understanding the impact and the course of the disease. In part because cognitive deficits lie at the core of Alzheimer's disease, researchers have assumed that data collected from demented individuals is inherently unreliable and therefore not useful. This narrow view ignores the variability in the communicative abilities of individuals with dementia and reflects a very limited perspective on research methods that might be used to ascertain their views. Much can be gained from changing our view of the person with dementia from someone to be studied to someone whose perspectives can help us understand Alzheimer's disease. (p. 210)

Strengths of Choosing a Qualitative Methodology

Researchers who do choose to study the firsthand perspectives of persons with Alzheimer's disease are likely to find qualitative techniques most appropriate while conducting their research. Sabat (1994) aptly illustrates the strength a qualitative methodology provides while accessing this population by stating: "such accounts require

that the subjects of investigation retain their individuality and interactions with others rather than have those drowned in a sea of numbers that describes no individual in particular, but rather some often mythical ‘average person’” (p. 158). If a researcher is to use a survey, for instance, as his or her research instrument, he or she might know a great deal about the average person with Alzheimer’s (which keep in mind, is a scientific fiction), but would still be at a loss for an understanding of the meaning behind the individual’s behavior. “A genuinely rich understanding of human behavior is achieved through a methodology that socially contextualizes action and thought” (Jaffe & Miller, 1994, p. 55); hence implying that a qualitative method can help provide this level of understanding. Furthermore, a qualitative method provides the researcher freedom from adhering to a structured format with standardized probes more common in quantitative studies.

The subset of Alzheimer’s disease research that accesses the firsthand perspectives of the person with Alzheimer’s is still in the formative stages. As a result, the hypothesis testing so characteristic of quantitative studies is not as readily an option for researchers conducting studies in this field. Not only is this particular area of research not yet advanced enough for hypothesis testing, no sampling frame exists for the researcher wanting to speak with a variety of individuals who are diagnosed with the disease. Essentially, the benefits of designing qualitative studies while accessing this population are clear, as evidenced by other researchers who have done just that (i.e., Bartlett & Martin, 2002; Clare, 2003; Gillies, 2000; MacQuarrie, 2005; Pearce et al., 2002; Phinney, 1998; Sabat, 1994).

Although there are multiple justifications in choosing a qualitative methodology for a study of the firsthand perspectives of persons with Alzheimer's, there are also limits in using such a methodology to frame the research. Qualitative researchers should know that when they enter another's world, not only do they discover meaning, but they also bestow it; hence, researchers of this type cannot avoid finding themselves in the position of being a co-creator of meaning alongside their research subjects. Research, essentially, is a dynamic process, as the researcher's ideas affect the way she or he perceives the participants' experiences (Pearce et al., 2002).

In order to deal with the methodological and conceptual ramifications that follow, scholars have the responsibility of problematizing meaning in their research (Jaffe & Miller, 1994). The researcher's simple awareness of his or her influence on the meaning of his or her participants' experiences helps problematize meaning. Put more simply, scholars have the duty of examining their own social roles and how these relate to their interactions with their subjects. The research does not only consist of the subjects' world, as it is more of an interacting meaning system between the scholar and the participants (Jaffe & Miller, 1994). It is inaccurate to assume that the researcher stands outside of the phenomenon she or he is studying, reporting from an objective stance on his or her participant's experiences and perspectives.

Not only is it imperative that researchers (both qualitative and quantitative alike) be aware of the effect their social contexts have on the data they discover and create, but they also need to be aware of the effect their data may have on them. Because scholars do not occupy as detached a stance from their data as some positivist researchers might

believe, they should consider their “closeness” to both the data and their participants throughout the research process. Scholars must be aware of their own cognitive and emotional experiences while conducting research, and to value that awareness. This is essential because their own personal experiences with what they encounter while researching will also have an impact on the knowledge they discover, report and co-create with their participants (Jaffe & Miller, 1994).

Institutional Review Boards and Informed Consent

Researchers of any population need to be well aware of the impact their Institutional Review Boards will have on their study’s design and execution. They must also be ready to address issues regarding obtaining consent from their participants. Those who study persons with Alzheimer’s however, must be even more mindful of such issues, as they will affect the research process and outcomes. The following sections provide an explanation for the necessity of IRBs and informed consent as well as examples of issues researchers can expect to encounter while determining how to obtain consent from their participants.

The Need for Institutional Review Boards and Informed Consent

The nature of inquiry requires researchers to attain a level of intimacy with participants which results in the constant potential of facing ethical issues (Sankar & Gubrium, 1994). The IRB is an organizational entity whose primary purpose is to protect human research participants, helping to decrease the likelihood that scholars will encounter negative ethics related situations. The development of this particular type of ethics committee was a necessary response to previous research abuses (Kayser-Jones &

Koenig, 1994). IRBs weigh the potential risks and benefits posed to participants in order to determine whether the person's participation is worth the risk involved (Kayser-Jones & Koenig, 1994). The reason I call attention to the function of IRBs is because those who study the experiences of persons with Alzheimer's need to be constantly aware of the potential effects (both positive and negative) their IRBs will have on their research, especially considering the vulnerability of the population (Alzheimer's Association, 2004; Pratt, 2002).

In similar fashion to the IRB, the topic of informed consent is important with any research study involving human participants (Kayser-Jones & Koenig, 1994), as the individuals' consent often determines whether the project can proceed (Guinn, 2002). Normally researchers are able to assume their participants are capable of providing informed consent (Loue, 2004). Those studying persons with Alzheimer's, however, need to be even more cognizant of the issues surrounding informed consent and have the ability to assess whether their participants have the capacity to provide it before they participate (Bartlett & Martin, 2002; Hubbard, Downs, & Tester, 2002; Loue, 2004). DeRenzo, Conley, & Love (1998) help illustrate the need for obtaining informed consent by showing the lack of understanding participants often have regarding their research participation with the following:

[There is a] growing body of literature that demonstrates poor quality of understanding and retention by research subjects of the informed consent process; and there is consistent evidence of confusion on the part of the researchers and subjects about distinctions between research and clinical care. (p. 75)

Although all research involving persons with Alzheimer's (as well as with any human participants) invariably brings investigators into contact with an IRB and the topic of informed consent, few published studies actually report these processes (Bartlett & Martin, 2002). For example, some researchers (i.e., Clare, 2003; Pearce et al., 2002) studying this population mandated participants be able to provide consent; their reports, however, did not include how the researchers obtained consent. In similar fashion, one author (MacQuarrie, 2005) at least mentioned the consent process, but did not describe how it was constructed, while others (i.e., Gillies, 2000; Sabat, 1994) chose not to discuss consent issues whatsoever. In sum, reports on the topics of IRB approval and informed consent are necessary to guide future researchers endeavoring to survey this population (Alzheimer's Association, 2004; Loue, 2004), however are not in high supply.

Issues Surrounding the Informed Consent of Persons with Alzheimer's Disease

Although it is clear that researchers need to obtain consent from their participants, they also need to ask: does the individual even have the capacity to be involved in making a decision to participate in the research (Bartlett & Martin, 2002)? For a researcher to deem a participant as having the capacity to consent to research, the participant must have "the ability to comprehend a research protocol, the meaning of personal participation in this protocol, including risks and benefits, as well as the ability to make and communicate a choice about participation" (Alzheimer's Association, 2004, p. 172). Participants also need to understand that their research involvement might not offer any direct clinical benefit (Loue, 2004).

Proxy consent is common when the person with Alzheimer's is legally incompetent. This population, however, often objects to their caregivers providing consent (Dewing, 2002). When scholars pursue proxy consent, they exclude the person with Alzheimer's from the process, as the attention is then focused on the caregiver and the researcher. What happens if a caregiver provides consent, but the person with Alzheimer's does not want to participate? Although there is utility in using a proxy (and whereby competency-based) model for providing consent, it often results in the person with Alzheimer's occupying a passive role in the process. Regardless of whether she or he fully can provide informed consent, researchers still need to ensure that the person with Alzheimer's is a part of the process (Dewing, 2002).

Essentially, researchers should be most concerned about assessing their participant's ability to make a decision, rather than determining the person's level of competency. For instance, an older adult who is unable to manage his or her finances might still be able to make the choice to participate in a study (Kayser-Jones & Koenig, 1994). Researchers who forego competency-based or proxy consent models need a variety of strategies in determining if and how their participants will be able to provide them with informed consent (Bartlett & Martin, 2002).

Fortunately there are some options for those who study this population in determining whether the person with Alzheimer's can provide informed consent, such as, the use of cognitive testing scores or capacity assessments. For example, an option that moves away from obtaining proxy consent involves the use of the Mini-Mental State Examination (MMSE; a cognitive mental status examination developed by Folstein,

Folstein, & McHugh, 1975). If a researcher so decides, she or he may use the person with Alzheimer's scores on the exam to determine whether the individual can provide informed consent. In using this tool, however, there is a potential risk that a participant's poor performance can result in his or her loss of dignity (Kayser-Jones & Koenig, 1994).

Another way of obtaining informed consent is to measure a participant's understanding of the research process. In one study on people with dementia, the consent form included a series of questions designed to show that participants understood the aims of the research (Hubbard et al., 2002). The use of such screening tools has become a current trend among IRBs (as in the case of the University of Maryland). In this way, researchers are able to determine whether participants have the "capacity to understand to what they are consenting" (Resnick et al., 2007, p. 75).

The Evaluation to Sign Consent (ESC) is an example of one screening tool available to researchers studying this population (Resnick et al., 2007). The ESC is a short, five-item questionnaire designed to help scholars determine whether participants understand their participation in the research study in which they are involved. Essentially, this measure helps move beyond cognitive testing to evaluate an individual's ability to provide consent (Resnick et al., 2007).

Raymond Love (a pharmacist at the University of Maryland) developed the measure with the purpose of evaluating the ability of people to consent in clinical situations (DeRenzo et al., 1998). The main tenet of this measure is to address the understanding of participants, as it is often the case they are unable to describe correctly the research to which they are consenting. If participants answer all five questions

correctly, they have demonstrated an adequate understanding of the research and can be considered able to provide ethically valid consent (DeRenzo et al., 1998; Resnick et al., 2007). Researchers (i.e., DeRenzo et al., 1998; Resnick et al., 2007) have shown that participants do have the ability to pass the ESC, although it may be insufficiently rigorous and therefore too easy to pass.

Another type of capacity assessment available for those who study this population is the MacArthur Competence Assessment Tool-Clinical Research Version (MacCAT-CR; as outlined in DeRenzo et al., 1998). This measure, however, is much longer than the ESC and asks questions about a hypothetical study, whereas the ESC focuses on specific study facts. According to DeRenzo and colleagues (1998), more highly developed capacity assessments are lacking, as this field of research is still in the formative stages. When referring to the MacCAT-CR and the ESC, they explain:

[They are] only initial attempts at what will require study and refined study if a truly valid and reliable assessment-of-capacity-to-give-consent-to-research tool is to be successfully developed and widely used. We see these two assessment tools as book ends to a process that promises to eventually produce a solid assessment instrument. Such an instrument is badly needed. (p. 28)

Three primary issues that surround the topic of capacity assessment are the embryonic nature of scholars' abilities to assess decisional capacity, debates of who should be included in the consent process, and the need to develop more refined assessment tools (DeRenzo et al., 1998). Mindful of this, the research community needs to constantly ask themselves if their participants are sufficiently capacitated to provide consent, as well as, how can they tell?

Lastly, upon identifying how they will assess participants' ability to provide consent, researchers must also consider the conditions under which they are conducting these assessments. Certain conditions could adversely impact an individual's performance on a capacity assessment (Loue, 2004). Those who study this population need to concern themselves with who will be conducting the assessment, as it is sometimes the case researchers employ a third party for the purpose of doing just that (DeRenzo et al., 1998). During the consent process, they need to talk openly with the person with Alzheimer's in a way that involves him or her, giving the person the choice to participate. In doing so, scholars can begin to correct the previous tendency to fail to consider this individual as being of primary importance in the process of informed consent (Dewing, 2002). This being said, researchers must carefully think through the methods they take to demonstrate whether participants are able to provide consent and be aware of any implications that might follow.

The Role of Professional and Family Gatekeepers

The issue of obtaining informed consent is but one of many when accessing the firsthand accounts of persons with Alzheimer's. Researchers will also invariably encounter negotiating with a wide array of gatekeepers, ranging from health and aging professionals to family members and other loved ones of the person with Alzheimer's (Bartlett & Martin, 2002). These various "protectors" play an important role in facilitating the individual's research participation (Pratt, 2002). Family members often control access to this population, either by giving permission for and even setting up the interview (Bartlett & Martin, 2002) or by prohibiting it altogether (Pratt, 2002).

In accessing a population that can either be overprotected or exploited, it is the responsibility of researchers to protect their participants (Loue, 2004). Likewise, gatekeepers have a valid role in protecting this population and can be a valuable resource to the researcher. These individuals can increase the likelihood the person with Alzheimer's will participate in the research, help facilitate the interview process (such as by explaining the research to the person and reminding him or her of the arrangements), and can monitor the person with Alzheimer's after the research has taken place (Pratt, 2002). Regardless of the presence of gatekeepers, investigators still must ask themselves whose voice dominates in whether the person with Alzheimer's will be included in the research (Bartlett & Martin, 2002). Quite simply, is it the professional's, the caregiver's, or the person with Alzheimer's?

Family members' (and professionals') views on research often have an effect on whether they permit access to the population. Likewise, potential biases on behalf of professionals toward their clients can result in them choosing one individual over another for research participation (Bartlett & Martin, 2002). Persons with Alzheimer's might also be coerced by others to participate (Bartlett & Martin, 2002) and might be afraid that their choice not to participate could result in negative treatment from service providers (Loue, 2004).

In sum, researchers must be mindful of the role of professional and family gatekeepers during the course of the research. Regardless of whether they aid in or the research effort, these are individuals whom researchers will undoubtedly encounter and need to be prepared in doing so. By adequately expressing their research goals and by

showing that they will pose no harm to the person with Alzheimer's, researchers can then better negotiate with protective gatekeepers in order to access this population.

Researchers should be mindful, however that gatekeepers might not be in agreement with all research goals, especially if such goals call into question their performance as a care provider.

Interviewing Persons with Alzheimer's Disease

After a researcher has received IRB approval, has determined how to obtain informed consent from his or her participants and has successfully negotiated the maze of protective gatekeepers, he or she is ready to begin collecting data. The most noteworthy task begins here for those pursuing the firsthand accounts of persons with Alzheimer's. Using the person with Alzheimer's words to tell his or her story requires techniques which researchers of other populations need little knowledge. Investigators must be able to sort through the cognitive impairment and piece together what the person with Alzheimer's is trying to communicate to most accurately portray that individual's experience.

The following section outlines difficulties researchers face in conducting interviews, demonstrates the need for techniques while interviewing this population, and provides examples that can be beneficial during the interview process. It then concludes by addressing the emotional awareness of researchers who interview persons with Alzheimer's.

Potential Difficulties

Although Booth and Booth's paper (1996) on interviewing inarticulate subjects was specifically on individuals with learning difficulties, it provides appropriate examples of the situations researchers can expect to encounter while interviewing persons with Alzheimer's (as Clarke & Keady also show, 2002). This population often demonstrates an inability to communicate, possesses limited language skills, and lacks the ability to answer particular types of questions. Researchers may expect to find difficulties in realizing what the person with Alzheimer's is communicating because of his or her inarticulateness, problems with understanding time sequences, and his or her simple inability to answer questions (Booth & Booth, 1996; Clarke & Keady, 2002).

Another potential challenge for researchers interviewing this population involves the person's difficulty in moving from lived experiences and actual events to an abstract level of thinking. A typical interview normally requires the interviewee to be able to reflect on past events. For the person with Alzheimer's, however, this ability is not as readily available as would be for a cognitively intact individual.

Techniques While Interviewing

Although researchers face challenges in interviewing persons with Alzheimer's, these challenges do not completely prohibit this population from being able to tell their stories. The implication here is that researchers of persons with Alzheimer's need to know techniques for interacting and engaging with this population. They need to come to the realization that any difficulties they encounter during the interview process might be due to their methodology rather than the person they are interviewing and they should be

willing to utilize unorthodox methods accordingly (Booth & Booth, 1996). If investigators fail to acknowledge the deficiencies in their methods and continue to assume they cannot access the person with Alzheimer's perspective, they will continue to exclude persons with Alzheimer's from research studies (Booth & Booth, 1996). Quite simply, scholars must be willing to acknowledge and compensate for their own methodological limitations.

Conducting interviews with this population is essentially an art form requiring the interviewer to learn how to communicate in a way that is relevant to the participant. As Goldsmith (1996) describes, communication with a person with Alzheimer's is like tennis with a coach: the concern is not about the score but is rather with keeping the ball going back and forth, with the interlocutors going wherever necessary within the interaction in order to understand what the other is saying.

In the beginning of the interview, it is critical to establish rapport with the respondent and learn how best to connect with him or her (Clarke & Keady, 2002). Those conducting the interview must engage in a communicative style that does not make the respondent feel inadequate and should avoid having any fixed assumptions of the individual's ability throughout the interview process (Booth & Booth, 1996). "The researcher must reach towards the person with dementia rather than the person with dementia having to reach into a cognitively demanding reality in which they become incapacitated" (Dewing, 2002, p. 164).

Interviewers of this population must learn how to slow down and wait and train themselves not to finish the participant's sentences for him or her. In doing this, those

who conduct the interviews allow both themselves and respondents time to process the words and meanings being exchanged. Although the interviewer will likely have to modify his or her style of communicating, he or she should not use patronizing speech patterns as if speaking to an infant. Sometimes people change the tone of their voice in a high-pitched way when speaking to elders or by making explanations for things the elder is already aware. Generally, any time an interviewer modifies his or her speech to “talk down” to the person with Alzheimer’s, he or she is diminishing that individual’s dignity. The interviewer also must not be afraid of silence during these interviews, as it might take the individual time to collect his or her thoughts before responding (Goldsmith, 1996).

Keeping questions simple and direct is also important, as is keeping talk (by the interviewer) to a minimum (Clarke & Keady, 2002). Sometimes it is hard for respondents to follow the line of questioning unless the investigator speaks in short sentences (Goldsmith, 1996). Forced choice questions normally elicit more response, as participants often feel the need to explain themselves (Schatzman & Strauss, 1973). Interviewers should not ask leading questions that would evoke a desirable response (Goldsmith, 1996) and keep in mind that respondents often have a higher level of discernment than their conversation reveals (Booth & Booth, 1996).

Likewise, researchers need to consider what information they really need. They need to avoid focusing so much on insignificant details that are difficult to for the person with Alzheimer’s to remember; for instance, instead of asking about specific facts, asking about general feelings or experiences (Pratt, 2002). Researchers also need to be less

concerned about dates and events (Pratt, 2002) and should hesitate to ask about time sequences (Clarke & Keady, 2002). Simply knowing the boundaries of what to ask and not to ask is important in interviewing persons with Alzheimer's. Interviewers need to avoid having the interview become like an interrogation, while also keeping in mind that participants might not provide clues for them to know which questions to ask next (Booth & Booth, 1996).

A variety of factors may affect the person with Alzheimer's ability to communicate, such as the time of day, background noises, location, and general fatigue. For instance, it would likely be preferable to schedule interviews on sunny days instead of overcast ones because of the difficulties persons with Alzheimer's normally experience in inclement weather. Likewise, the person's home is often the best location for the interview (Cotrell & Schulz, 1993; Clarke & Keady, 2002; Wenger, 1994) because it gives the individual more control over his or her environment. Some researchers (i.e., Clarke & Keady, 2002) consider service provision sites as the least desirable for interview locations.

The option for researchers to conduct interviews over multiple encounters is valuable because the respondent might not be able to recall specific topics but during another visit might be able to speak about the same topic completely clearly (Goldsmith, 1996). Researchers should keep in mind that if they are conducting multiple interviews with the same respondent, she or he might not remember prior visits (Pratt, 2002). Regardless of whether the researcher is conducting one interview or multiple ones with each respondent, she or he needs to be prepared to clarify his or her role during each

encounter. During the interview, the person with Alzheimer's might either forget who the interviewer is or might confuse him or her with being a social worker, nurse, or doctor (Pratt, 2002).

Researchers need to make sure the interviews are safe and positive experiences for respondents (Pratt, 2002). Knowing how to introduce the topic of Alzheimer's is of great importance in order to maintain this endeavor. Researchers must not assume that the person with Alzheimer's is aware or even able to discuss his or her diagnosis. Interviewers need to be careful not to disclose accidentally the individual's diagnosis to him or her if the person is either unaware or lacking the insight of it. Pratt (2002) suggests a variety of strategies in how to discuss the diagnosis with the person with Alzheimer's safely, such as allowing significant others to inform about the person's knowledge of his or her diagnosis, avoiding disclosing the diagnosis at whatever cost, and allowing the person to initiate any discussion on his or her diagnosis. Were a study to primarily focus on living with Alzheimer's disease, for instance, the researcher would need to make sure prior to the interview the person with Alzheimer's knew about the diagnosis and was willing to discuss the topic. In this situation, theoretically speaking, the researcher should have few problems in introducing the topic of Alzheimer's disease and therefore could ask direct questions about the individual's experience.

The potential for the person with Alzheimer's to become distressed is another situation the interviewer should be prepared to encounter, as emotionally charged topics will likely arise during the interview. This in consideration, the researcher should be willing to take breaks, avoid topics and if need be, terminate the interview altogether

(Pratt, 2002). Interviewers should be open to discussing non-distressing topics, but also need to know that the interviewee might want to talk about his or her distress (Pratt, 2002) and be welcoming of the opportunity to discuss his or her experience (Cotrell & Schulz, 1993). In this situation, the interviewer needs to validate the individual, communicate the idea that his or her views are acceptable and important (Schatzman & Strauss, 1973) and reduce his or her anxiety by whatever means necessary (Clarke & Keady, 2002). Were a participant to become emotionally distressed, the interviewer should be willing to contact a loved one to help reduce the person's anxiety or should simply remain with the individual as long as necessary, possibly assuming the role of an informal counselor.

The Researcher's Emotional Response

The interviewer's position requires him or her to have a certain level of emotional attachment to his or her respondents in order to validate their experiences. This position inadvertently violates the norm of holding a detached stance as a researcher (Clarke & Keady, 2002). Investigators need to take detailed field notes about their experiences and responses to interviewing, which can in turn help them process their own grief and help them deal with their emotional response, whereby allowing them to be present as a genuine person and not just a researcher (Pratt, 2002).

The combination of potential difficulties, necessary techniques, and the importance of one's own emotional awareness strongly imply that a scholar's normal working skills rarely equip him or her for the job of interviewing persons with Alzheimer's. Regardless, this population is desperate to be heard (Goldsmith, 1996).

Essentially, researchers need to place more focus on overcoming barriers to hearing these individuals instead of focusing on their limitations as interviewees (Booth & Booth, 1996). Scholars can do this by acquiring the skills that will help them to understand and interpret these individuals' views (Goldsmith, 1996). If the research community really does want to place persons with Alzheimer's as the primary informants of the disease experience, they cannot continue to disregard the development of Alzheimer's friendly research methods (Clarke & Keady, 2002).

Summary

In conclusion, researchers should no longer forego the firsthand perspectives of persons with Alzheimer's while conducting research on the experience of the disease. Those who choose to access this population can expect qualitative methods to be generally appropriate while designing such studies. Scholars must also be mindful of the role IRBs will play in shaping their research and need to be prepared to address such topics as obtaining informed consent from a vulnerable population. After having navigated the IRB approval process and having determined how to demonstrate participants' capacity to provide consent, investigators should be ready to encounter a host of both professional and family gatekeepers during the data collection process. Upon having approval to proceed with the interview from all parties involved, researchers must be equipped with the appropriate interviewing skills required for surveying this population. Lastly, those who study these individuals should consider unorthodox methods and techniques in order to conduct interviews that elicit information that adequately portrays their participants' experiences.

CHAPTER III

METHODOLOGICAL RESULTS

As discussed in the previous chapter, methodological reports on accessing this population are insufficient for a researcher who is seeking guidance in conducting studies using firsthand accounts. This chapter provides a detailed account of the situations I encountered from start to finish during the present study in order to aid other researchers in pursuing the perspectives of persons with Alzheimer's. This chapter begins with a discussion of how I decided to frame the research, followed by a mention of the resistance I met during the formative stages of the study along with my choice to employ a qualitative methodology.

This chapter also provides a detailed account of the development of this study, from the formative stages of my relationship with the IRB to my decision of how to obtain informed consent from participants and finally, to the IRB's approval. Following a brief mention of my initial population is an in-depth charting of the recruitment process which is included to illustrate why it proved difficult to survey this population. A discussion of the expansion of my population parameters and the study's overall changes follows, along with a description of the data collection process, including obtaining informed consent and interviewing the participants. The chapter concludes with my analysis of the data and a summary of the topics outlined.

This chapter's in-depth description of the research process combined with a set of specific guidelines in the following chapter is intended to aid researchers when studying this population. Quite simply, this field is in need of more accounts that offer such guidance for working with this specific population.

The Use of Firsthand Accounts

As previously mentioned, there is a commonly held belief among researchers, professionals and the lay community alike which maintains that persons with Alzheimer's are unable to offer their perspectives for participation in research. I encountered this belief on more than one occasion throughout the course of this study, as both professionals in the field of aging as well as significant others in the lay community met me with an attitude of disbelief that I would be able to conduct interviews with the population. As a result, I found myself in an educational role, having to explain that people with Alzheimer's often do retain the ability to offer their perspectives.

I proceeded with my original intent despite adverse opinions. I have attempted to keep the person with Alzheimer's perspective the primary one since the beginning of this project and have been able to uphold that for the most part. Apparently, I was not alone in meeting resistance in endeavoring to seek out the accounts of this population, as others (i.e., Goldsmith, 1996; Wilkinson, 2002) have documented similar responses.¹ Essentially, the fact that a person with Alzheimer's disease would have something to add to what researchers know about the disease experience is relatively new and often discounted (Goldsmith, 1996).

¹The former of these two researchers encountered the belief of others that he was wasting his time in pursuing firsthand perspectives.

With the current study, I have identified myself with a category of researchers causing a shift toward a knowledge base originating from persons with Alzheimer's perspectives. By directing my attention to the firsthand accounts of these individuals and by treating them as vital contributors to research about the disease, I consciously forsook the biomedical and caregiver focused framework handed to me by the research community at large.

The Use of a Qualitative Methodology

Upon deciding to access the firsthand accounts of persons with Alzheimer's, I needed to choose an appropriate methodology that would enable me to answer my research question: what are the patterns that characterize mixed friendships? For the study, I wanted to be able to hear individuals with Alzheimer's disease speak about their friendship experiences and chose to rely on a small number of individuals to provide me with an in-depth understanding of the topic (Clarke & Keady, 2002). I was able to capture the subjective experiences of my participants by designing a qualitative study (Bartlett & Martin, 2002; Wilkinson, 2002) and gain insight into these individuals' worlds of meaning (Sankar & Gubrium, 1994) surrounding their friendship related behaviors. Essentially, I preferred qualitative to quantitative research because of the possibility it afforded me to explore the meaning behind my participants' behavior, my intention to conduct exploratory research, and the lack of a sampling frame (as there was no centralized list of individuals I could interview for this study).

The IRB and Informed Consent

The Institutional Review Board, while playing a critical role in monitoring research had a significant impact on how I conducted my research. This next section reports the formative stages of my relationship with the IRB, my decision of how to obtain consent and finally, the IRB's approval of the present study.

Preliminary Contact with the IRB

Almost seven months prior to receiving IRB approval, I began making periodic contact with my departmental reviewer who was designated as my point of contact for the IRB, making him aware of what I was hoping to study. He encouraged the idea of pursuing the perspectives of persons with Alzheimer's and assured me the topic was worth inquiry. During these initial interactions, we discussed the population members' competence and vulnerability and the possibility of the study going to full review.²

The timing in which my IRB application was submitted and the Board provided its approval were contingencies that would affect when I would be able to proceed with collecting data, hence, interviewing participants. I completed the first draft of my 27 page IRB application in time to submit it for review at the IRB's upcoming meeting.³ Before I even completed the application however, I had to address the question of how the person with Alzheimer's would provide informed consent.

Obtaining informed consent is paramount (Jaffe & Miller, 1994), as IRBs have a major responsibility to make sure the potential participants can make an informed

² 'Full review' is the highest level of review a study can go through requiring the entire IRB to meet and review the research proposal.

³ There were only two full review meetings scheduled during that particular time frame, meaning waiting for the second meeting could result in a long delay in data collection.

judgment and are not exploited by researchers (Guinn, 2002). This was one of the most difficult methodological issues faced throughout the entire course of this study. As previously mentioned, the reason why obtaining informed consent is an uncertainty with researchers sampling this population (Pratt, 2002) is because persons with Alzheimer's are sometimes unable to provide it (Alzheimer's Association, 2004).

Before taking an in-depth look at how I addressed issues surrounding the consent process, it is appropriate to mention that the National Institute on Aging reviewed consent issues with cognitively impaired populations during this same time period. Five months after I had determined how to obtain consent in the present study, the Office for Human Research Protections sent out a call to researchers to investigate whether additional guidance and regulations were needed to protect potential subjects with impaired decision-making capacities. I mention this to demonstrate that apparently I was not the only researcher who had grappled with consent issues with a cognitively impaired population.

Determining How to Obtain Consent

In determining how to obtain participants' consent, the primary task at hand was to demonstrate the person with Alzheimer's had the capacity to make an informed decision. Initially both my faculty advisor and IRB departmental reviewer suggested I obtain declarations of competency from my participants' medical doctors (MD). If I decided to heed this advice and seek out this piece of information from the participants' MDs (when there was one), I would have potentially faced a dilemma in accessing

personal health information (PHI). Were I to have accessed PHI, I would have invariably come into contact with HIPAA regulations which I had no desire to do.⁴

Without a formal declaration of competence from the participants' medical doctors, I was unsure of how to determine whether participants could or could not provide consent and whether they should even be the ones to provide it. Should a Legally Authorized Representative (LAR) have provided consent when there was one, and if there was no LAR, would just any caregiver have sufficed (again, assuming there was one)? If the individual had been unable to provide consent, I would have needed to obtain permission from a proxy who had both the capacity and legal authority to consent and would then have also needed assent from the person with Alzheimer's (Alzheimer's Association, 2004). If the participants had been competent, however, it would have been completely inappropriate and disempowering to have had another party provide consent, essentially making the decision for them (Dewing, 2002). Oftentimes many persons with early-stage Alzheimer's complain of a loss of a sense of control (Gwyther, 1997) and as a researcher wanting to hold their perspectives primary, I did not want to add to that in any way. Not only that, but were I to have used this kind of "double consent," I would still have failed to address whether my participants were actually capable of providing informed consent.

Again, prior to filling out the IRB application, I needed to determine how to obtain informed consent. Aside from an MD's declaration of competence or proxy consent, another option I had included administering an MMSE to participants, using

⁴ The Health Insurance Portability and Accountability Act of 1996 is a federal law enacted to protect the privacy of personal health information (United States Department of Health and Human Services, no date).

their scores to determine their ability to provide consent. I hesitated to do this, because I had no desire to be in the position of conducting a cognitive aptitude exam with my participants. Not only that, but basically I would have been screening more so for their cognitive impairment rather than screening for their capacity to consent to research (Alzheimer's Association, 2004). Essentially, I would have learned the individuals' level of cognitive impairment, but still would have been unaware if they were able to provide consent. I could have decided to use participants' most recent scores on the exam, assuming they had taken one, but was advised by another scholar (with experience researching persons with Alzheimer's) that the scores would not necessarily be reflective of the participants' decision-making capacity. This being said, there were simply no easy answers in determining how to obtain informed consent from these individuals.

Fortunately, because I only planned to conduct one interview per participant, I was not concerned about changes in cognition over the course of the study having an effect on the participants' capacity to provide consent. Were I to have interviewed participants over multiple points in time, I would have needed to be concerned with formally assessing their capacity each time, and if I was unable to obtain it, would have needed to seek permission from a proxy (Alzheimer's Association, 2004).

The Use of a Capacity Assessment

After much reading and some corresponding with researchers who had experience dealing with consent issues in this population, I decided to focus my attention on the person with Alzheimer's ability to understand the key points of the study. I decided to conduct a capacity assessment (which introduced methodological issues in and of itself

that I outline later), and thereby avoided administering a cognitive aptitude test (such as an MMSE) to participants. Essentially, I assumed the participants (regardless of cognitive ability), had the capacity to consent if they could demonstrate an understanding of the research study and the impact their participation would have on them (Resnick et al., 2007). By using the assessment to determine the participants' capacity to provide consent, I examined whether they possessed: an understanding of the study, an appreciation of the risks versus benefits for their personal situation, an ability to reason out the risks versus the benefits, and the choice to participate (Alzheimer's Association, 2004; Resnick et al., 2007).

A member of my thesis committee (Janice Wassel) directed me to the Evaluation to Sign Consent measure (ESC; Resnick et al., 2007). Upon studying it and adjusting it for appropriateness in the current study, I answered the question of how to determine whether my participants could provide consent.⁵ My decision to use this rather than proxy consent made it more difficult to locate participants for the study. Were I to have used proxies and not to have mandated that the person with Alzheimer's be able to provide informed consent, it would have resulted in far more interviews. I return to my use of this measure during the consent process after further discussion of the IRB approval process.

Obtaining the IRB's Approval

Determining how to show whether participants could provide consent enabled me to complete my IRB application. This document included the application itself, the

⁵ I renamed the ESC the Capacity to Sign Consent (CSC) only for the purpose of this study due to the minor modifying of questions I did prior to administering it.

questionnaire I proposed to use to determine the participants' capacity to provide consent, the justifications for the use of this questionnaire, a flyer I used while recruiting for the study, the actual interview guide I proposed to use while collecting my data, proof of Research Training for Human Participants for both myself and my faculty advisor, and letters of support from the agencies who were helping me with recruitment. After submitting the document I was notified that my departmental reviewer had decided that the study required a "full review." Accordingly, my faculty advisor and I appeared before the Board to respond to questions concerning the study's methodology. Questions and concerns of the IRB included how many questions on the CSC the participant would need to answer correctly in order to provide consent, whether to keep the interviews private between myself and the participant as opposed to allowing a loved one to be present, and how to deal with the potential for participants to become emotionally distressed during the interview.

As a result of the IRB's "full review" a number of guidelines were required for the study, only one of which I would not have chosen. That particular mandate was that I allow participants to have a third party present during the interview if they so desired. Originally, I had planned one-on-one interviews with participants and was of the opinion that the presence of another individual could potentially affect the respondent's answers or even prevent the respondent from answering altogether. From the inception of this project, I intentionally tried to keep the focus on the perspective of the person with Alzheimer's and was concerned that by having another to be present during the interview,

I would compromise this value. I later discuss how this guideline was useful, despite my initial resistance to it.

The IRB chairperson also mandated that in order for the IRB to approve the project, the participants have the legal ability to provide consent, as opposed to just having the cognitive ability, as evidenced by answering all five questions on the CSC correctly. This required the addition of a line on the consent form that stated: “You also agree that you are legally able to provide consent for your participation in this study.”

Lastly, the IRB mandated that if a participant became emotionally distressed during the interview, I would then assist her in contacting someone to help deal with her feelings.⁶ With this mandate, it was clear that the IRB was concerned that I would not know what to do was the participant to react negatively to the questioning. I made the IRB aware, however, that I had previous experience in dealing with this population during an internship at an assisted living facility exclusively housing individuals with memory impairment.

Initial Population

Although I originally intended to interview fifteen triads of persons with Alzheimer’s, the individual they identified as their good friend and their caregiver (assuming there was one), upon realizing how large of an undertaking this would be, I decided only to pursue the perspectives of the person with Alzheimer’s. Prior to necessary changes in the inclusion criteria (that I later discuss), the population for this study was Caucasian women with Alzheimer’s disease who lived in North Carolina. I

⁶ I was very agreeable with this requirement, realizing that it would protect me and the participants.

used non-probability sampling methods while recruiting participants because there was no centralized database of persons with Alzheimer's living in this state.⁷ To be eligible to participate in the study, the participants had to be English-speaking, Caucasian women with a diagnosis of Alzheimer's disease, age 65 years and older, who were still living in their homes, and who were able to understand the interview process and legally able to consent. Lastly, these women also needed to know about their diagnosis in order to be able to discuss it during the interview.

Such a narrow inclusion criteria originated both from the desire to have a homogeneous group with which I could easily make comparisons, as well as from the negotiations with my thesis committee and the IRB.⁸ Locating such a sample proved challenging at best.

Recruitment of Participants

To locate participants for this study, I attended aging conferences and workshops around the state with the primary goal of networking with professionals in the field who could connect me with the population of interest. I contacted over 85 different agencies overall, making professionals aware of my goals, promoting the study, with the hopes of finding women to interview. The main types of agencies I contacted were Area Agencies on Aging, other county or state governmental agencies, geriatric care managers,

⁷ In his study of persons with HIV and AIDS, Ueno (1998) also used non-probability sampling methods due to the lack of a readily available list of participants.

⁸ For instance, although I was interested in interviewing African American women, an advisor suggested that I would have a more difficult time in recruiting participants, thus leaving me the option of focusing on Caucasian women. Likewise, I also had not considered the need for participants to be able to legally provide consent until my IRB made the stipulation.

geriatricians, adult day centers, diagnostic centers for memory impairment, neurologists, and non-profit organizations which primarily serviced seniors.

The recruitment process was a learning experience in and of itself, as professionals continually told me that individuals with Alzheimer's and their caregivers often wait to access formal services until they absolutely need them. This trend meant that some of the very agencies I contacted to locate my population served individuals who were unable to participate in interviews due to the progression of the disease. Those likely to seek out such services would have had too high a level of cognitive impairment to provide informed consent, meaning that I would not have been able to interview them. When populations access formalized services, this is indicative of a level of need (Gillies, 2000), which can affect the recruitment efforts of researchers wanting to locate early-stage individuals. The lesson learned here was not to recruit participants from places like adult day centers, but rather to have focused recruitment efforts on diagnostic centers, where clients might have been more likely to be in the early stages of the illness. I also found that although the agencies I was contacting were in the field of aging, many of them had no direct contact with the geriatric population (i.e., the State Department on Aging and a county's Aging and Disability Resource Connection). Furthermore, even when an agency directly worked with the population, it was often the case that they simply did not have any clients who fit the study's population parameters at that time. The effort I had spent in contacting various professionals was not in vain, however. Even if a particular agency did not provide me with any potential respondents, the professional with whom I spoke normally offered the name of another professional who did.

After relentless recruitment efforts resulting without many participants, I learned that an early diagnosis of Alzheimer's disease is less common than I had originally thought.⁹ After corresponding with various professionals in the field of Alzheimer's and dementia, such as the director of a memory clinic, the Director of Education at an Alzheimer's Disease Research Center, and a respite care program director, I concluded that people do not receive a diagnosis of Alzheimer's in a uniform manner.

Medical doctors often hesitate to diagnose one with Alzheimer's and water down the dialogue, using such words as "memory problems" or "mild cognitive impairment" in order to avoid potential devastation for those who might have it. I heard firsthand one neurologist speak of telling a patient that he had mild cognitive impairment when the patient had clearly advanced in the stages of Alzheimer's disease. This physician's hesitation to diagnose the person helps illustrate the ambiguities of the diagnostic process. A side-note is that the lateness in most diagnoses cause persons with Alzheimer's and their caregivers to feel undermined and disempowered by professionals not being honest with them (Goldsmith, 1996).

In another situation, one caregiver son of a woman diagnosed with general dementia spoke of not bothering to have tests run for Alzheimer's disease (hence avoiding seeking out the diagnosis) because her medications would not change were she to be diagnosed, and ultimately, why bother? According to the director of one memory clinic, part of the reason why I found it so difficult to recruit participants was because (as in the case just mentioned) many individuals in the early stages of Alzheimer's have not

⁹ Clare (2003) also found it difficult to identify participants in her study on awareness in persons with Alzheimer's.

put that label on it. For those who do have the diagnosis, many have anosognosia and do not think they have a problem.¹⁰ Others simply do not want to talk about it. Lastly, one social worker informed me that some individuals with the disease simply choose to ignore the diagnosis while they are still functioning well. In sum, it appears that a diagnosis of early stage Alzheimer's is much less common than I had originally believed. After coming to this realization, I then understood why the diagnostic centers I had thought would be the most fruitful for recruitment efforts resulted in providing no participants for the study. Table 1 reflects my recruitment efforts as well as the number of respondents they yielded.

¹⁰ Lack of awareness of the disease process, written about in Clare (2003).

Table 1
Yield of Recruitment Efforts

Type of agency/ professional	Number of agencies/ professionals contacted	IRB approved agencies	Potential interviewees	Interviews attended	Interviewees providing consent
Special interest/ non-profit organizations*	5	1	4	4	3
Adult day centers	8	3	3	2	0
Senior centers	5	1	1	1	1
Area agencies on aging (AAA)	17	0	0	0	0
Geriatric care managers	9	1	1	0	0
Diagnostic centers	3	3	2	0	0
Other senior health professionals	6	0	0	0	0
Businesses in aging	1	0	0	0	0
Neurologists	4	0	0	0	0
Geriatricians	8	2	4	2	0
Non-AAA county or state governmental agencies	12	1	1	0	0
Other non-profit organizations	4	0	4	0	0
Universities	3	0	0	0	0
Total	85	12	20	9	4
Note. The organization that yielded the most interviewees was the Eastern Carolina Chapter of the Alzheimer's Association.*					

Modifications and the Final Population

Modifications to the IRB protocol were a continual process throughout the course of this study as a result of the efforts to recruit participants. Aside from obtaining the initial IRB approval, continually returning to the Board to seek permission to work with a new professional or agency was the primary IRB related challenge I faced throughout the recruitment process. Upon realizing that the agencies that the IRB had approved for the study were not generating potential respondents, I would then petition the IRB to add another. The modification process involved obtaining letters of permission from the agency with which I was proposing to work, filling out the modification application, having my faculty advisor sign-off on the application, and then allowing it to go through the IRB channels. When the recruitment process was finished, I had approached the IRB a total of five times. Although it clearly would have been more efficient to have only filled out one IRB application, I was simply unaware that the agencies through which I was recruiting would not generate an adequate number of participants for the study, resulting in me continually adding new recruitment agencies. By the time I had finished recruiting for the study, I had obtained IRB approval to work with the each of the following types of agencies: three memory impairment clinics (all affiliated with a university), an Alzheimer's Association chapter, three adult day centers, a geriatrician, a county division on aging, a senior center, a geriatric care manager, and a Geriatric Outreach Program of a university hospital.

Halfway through the project, I realized the need to change my inclusion criteria because of the seeming impossibilities of locating my originally defined population. As

previously mentioned, the inclusion criterion was a negotiation between my thesis committee, the IRB, and me; it was unnecessarily limiting, but I was unaware of this at the beginning of the study. Upon coming to an understanding of why it was so difficult to recruit study participants, my committee and I decided to include people in the early stages of any form of dementia in my population in addition to persons with Alzheimer's and to include people 60 years of age and older instead of the original requirement of 65 years and older. I found myself needing to find the balance between having the "perfect" or "ideal" study population versus one that was "realistic" or "findable." In the end, I decided to opt for a realistic population instead of an ideal one, which resulted in completing another IRB modification application and waiting on an approval before including people with dementia and those 60 years and older in my population. Had I known then what I know now, I would have relaxed the inclusion criteria at the beginning of the study.

Furthermore, I also chose to reformulate the study halfway through by changing it from a purely substantive one focusing on the friendships of persons with Alzheimer's to one that was also methodologically critical, focusing on the situations I encountered throughout the research process. I hoped that by allowing the study to evolve into something I did not previously expect, essentially a two-part thesis and by showing other researchers what I encountered while studying this population, that my experience would generate more future studies centered on the perspectives of people with Alzheimer's. Part of the strength of the study was the unexpected situations that arose throughout its course. Toward the end of the study my faculty advisor and I decided that instead of

interviewing fifteen people with Alzheimer's about their friendship patterns with cognitively intact individuals, I would interview five people with Alzheimer's or other dementia about their friendship patterns, writing a much more in-depth methods section than I had initially planned.

At the commencement of the study, altogether, my recruiters had made me aware of at least 20 potential participants. Eleven of these women either did not know about their diagnosis, had a caregiver who refused to allow them to participate, or had a caregiver who did not contact me to schedule an interview. For these reasons, I was unable to further pursue scheduling interviews with them. The remaining women were ones with whom I had been able to schedule an interview, numbering nine in all, only four of whom could provide informed consent.

After having gone from a population of 45 (which was never realistic) to 15, then to ten and again to five, the sample size decreased once again before the completion of the study, with four participants as my final count. Ten months after receiving IRB approval and beginning the recruitment process, my faculty advisor and thesis committee members allowed me to consider my data collection complete. Upon the commencement of the data collection process, I had traveled literally hundreds of miles from the northwest part of North Carolina to its southern coast in order to talk with women with Alzheimer's disease about their friendships. I document their stories in Chapter six. Immediately following, however, is an account of how I collected the data, specifically the consent and interview processes with the respondents.

Collecting the Data

The Informed Consent Process

The consent process for each participant began during the recruitment stages of the study. It was an ongoing and continual process involving multiple actors (professionals helping with participant recruitment, caregivers, and the participants themselves). Upon my initial contact with any given professional, she or he made contact with either the family caregiver or the person with Alzheimer's and explained the study. If the recruiter contacted the family caregiver, the family caregiver then spoke to the person with Alzheimer's and if the person with Alzheimer's was agreeable with being interviewed, I proceeded.

There were multiple layers of consent in that not only did professionals have to grant access to the population but in many cases family members did so as well. If any of the three parties (professionals, family members or the person with Alzheimer's) declined to participate, I would have been unable to conduct the interview. I encountered restricted access from each of these parties at one point or another throughout the recruitment process. I was unable to interview one potential participant because of a professional's reluctance to allow the agency which served her to aid in recruitment. Although there were no such restrictions with another professional with whom I had been in contact, two of her clients' caregiving daughters did not allow their mothers' participation. Lastly, there was a situation in which the professional and the caregiver both clearly were in favor of the potential respondent participating in the study. The potential respondent, however wanted nothing to do with it and refused to be involved.

Essentially, obtaining informed consent was a process from the time of recruitment and enrollment, throughout the study, and was not merely the signing of a document (Kayser-Jones & Koenig, 1994; Loue, 2004).

Prior to the actual interview, I read the consent form aloud or I had the participant read it, depending on what she preferred. After I presented the consent form, I read the questions from CSC (I provide both documents in Appendix A). If the participant answered all of the questions adequately, I then considered her able to provide consent and would proceed with the formal tape recorded interview. If she had not appeared to have an adequate understanding of her participation in the interview, I conducted an untaped mock interview, with the intention to preserve her dignity and to spare her potential embarrassment.¹¹ The fact that I asked participants to recount information that they had either just read or heard me read was clearly a methodological constraint. A hallmark symptom of Alzheimer's disease is short-term memory loss. The issue here was that I asked a population with known short-term memory problems to recount information I had just given them a few minutes earlier in order to be able to provide consent. In an attempt to surmount this situation, I asked each question slowly and allowed participants the time to process a correct answer. The simple act of patience during the consent process was the only option I had in order to facilitate the participants' consent and not violate IRB protocol.

¹¹ An idea approved by the IRB during the initial hearing.

The Interview Process

The primary caregiver of my participants (when there was one) typically acted as a conduit for me to schedule the interview. When it was practical, I called the participant or her caregiver the day of the interview to confirm. Each interview was a face-to-face encounter in a private setting, three with the caregiver present and one for which the caregiver did not attend.¹² I recorded the interviews in which the participants demonstrated the ability to provide informed consent.

At the beginning of the conversation, I introduced myself, explained why the interviews were important, and discussed how they fit into the larger study (Kaufman, 1994). I told respondents that I was a sociology graduate student who was interested in the experience of persons with Alzheimer's and was specifically interested in how friendships were affected by Alzheimer's disease.

For my research instrument, I used an interview guide (I include in Appendix A) similar to the one Sarah Matthews (1986) used in her study of friendships across the life-course. Like her, I asked participants general questions about friendship, including a section on demographic characteristics. In addition, my interview guide focused mainly on one friendship (whereas hers allowed the focus to be on multiple friends) and used the participants' experience of Alzheimer's disease to thread the conversation.

The primary methodological issue I faced in studying friendship and using this instrument to do it had to do with the definition of the word "friend." This word is used "to describe a variety of relationships ranging from short-term, superficial ones to long-

¹² Most interviews were in the participants' homes and one was in a secluded office in a senior center.

standing ones to which the persons involved are deeply committed” (Matthews, 1986, p. 11). In essence, the number of ways to define a friend is quite large. Another factor confounding this issue regards studying older adults’ friendships in particular. By the time an individual reaches old age, the number of people who have qualified as that person’s friend is enormous, whereby making it difficult for the older adult to keep distinct categories of friends, neighbors, and acquaintances (Matthews, 1986).

In order to eliminate any ambiguity surrounding the definition of friendship, toward the beginning of the interview, I asked participants to identify a good friend who we could discuss for the remainder of the conversation. Although I attempted to set parameters on the friend the participants identified, they still used their own definition of a good friend. For instance, even though I had asked her to define a friend to whom she was not related, one woman chose to speak about her niece for the course of the interview. Another chose not to speak about a particular friend at all and instead discussed her friendships only on a general level. Situations like this resulted in it being more difficult to make comparisons among the friendships I was studying.

During the interviews for which a caregiver was present, his or her input was useful. In one interview, for instance, the participant’s daughter was able to help her identify a good friend she had previously known. It was clear throughout the following conversation that the participant still thought the friend to be alive. I was under the same impression, with no reason to think otherwise, until the daughter clarified that the friend had died. Being without this piece of knowledge would have affected my report on this

particular respondent in a completely different way. I would have written erroneously about the friendship, as if it were still in existence.

In another interview, the only one for which a caregiver was not present, I struggled to understand the reality of what the respondent was saying. She was evasive when I asked her direct questions about her friendships. For example, after I asked her to identify a good friend, she answered the question ambiguously, which forced me to write about her friendships on a network level instead. Generally speaking, the presence of a caregiver in this situation might have been beneficial to the interview process, as it was evident her disease was having an effect on her communication style. Essentially, after realizing the benefit of having caregivers present during the interviews, I was thankful that the IRB had mandated their inclusion if the person with Alzheimer's so desired.

Generally speaking, the structure of the interviews was fairly fluid in that the participants and I moved back and forth between sections on the interview guide. Some of the threads of conversation had little to do with the interview guide as a result of the participant taking the lead. After completing the interview with my first participant, I realized the original six page guide was simply too long. I then condensed it in an effort to reduce both my and the participants' fatigue. The interviews averaged between one and one half hours in length. After all of the interviews except one, I went to an offsite location nearby (normally a parking lot of some sort) to take notes on anything that came to mind that might be of significance during my analysis of the data. I then transcribed each interview verbatim upon its completion.

Coding Analysis and Procedure

In preparation for the interviews, I constructed a list of themes that I generated during my search of the literature (I have included in Appendix B). Upon conducting and transcribing each interview, I used the *Ethnograph 5.0* (a computer program that analyzes text) to code the data. In doing this I was able to detect which concepts generated during my literature review were present in each participant's case. Not only did I examine the pre-existing themes but I also examined ones that surfaced during the interviews and looked for similarities and differences among the respondents. In identifying the emergent themes, I looked for statements that respondents mentioned repeatedly. I used the emergent themes to help answer my initial research question: what are the patterns that characterize mixed friendships?

Conclusions

After having collected the data, it was no longer a question to me as to why there was not much research conducted using the firsthand accounts of persons with Alzheimer's disease. The protection of the population, a lacking of adequate research methods, the ambiguities of the diagnostic process and the inability of many persons with Alzheimer's to provide consent by use of a capacity assessment are all potential barriers to this form of research. One purpose for the present study, however, was to offer a clear description of how I accessed these perspectives in order to encourage more researchers to conduct studies on this population. I offer more specific guidelines researchers can use in the following chapter. It is appropriate to end with a quote by Wilkinson (2002), a researcher who knows firsthand the nature of researching this population:

A central reason for the lack of research that includes people with dementia is the limited and fragmented understanding and experience of methods that are known to enable the voice of the person to be safely and effectively encouraged, heard and understood. Until very recently, the perception that people with dementia were unable to express feelings, opinions and views was widely held. This exclusionary view that assumed people with dementia could not be included is slowly being challenged as the practical difficulties of how to include people with dementia are gradually overcome. (p. 15)

CHAPTER IV

METHODOLOGICAL DISCUSSION

At the beginning of this project I recognized there was a paucity of studies centered on the firsthand perspectives of persons with Alzheimer's disease. I did not understand why this was the case, however, and proceeded with the current study. Throughout the course of research, it was continually evident as to why I found a relative lack of these perspectives in the research literature. Quite simply, it is difficult to access persons with Alzheimer's views! There are various reasons for this, with a primary one involving the lack of clear guidelines and reports in the existing literature on the topic. Because this field is in its formative stages, one would expect there to be in-depth accounts of how to go about pursuing the firsthand accounts of this population. This is not the reality of the situation, however, as methods sections in published accounts are normally ambiguous. In the spirit of not taking anything for granted while conducting this form of research, I have readily disclosed my experience in interviewing this population.

Although possibly intuitive, researchers of the population should know, for instance, that a qualitative method is often the most appropriate while charting the person with Alzheimer's experience. Likewise, navigating the IRB approval process will likely take a great deal of time and be challenging. The IRB shaped the present study by mandating that the person with Alzheimer's have a caregiver present during the interview

if she so desired. Initially, I had no desire for this to happen. Upon conducting the interviews, however, I was quite grateful that three of the four interviews had a caregiver present because of the caregivers' ability to provide a more complete picture of the participants' experience. Although the IRB process is regularly a topic of lament among researchers, going through it was clearly beneficial for the quality of the data in the present study.

My search of a proper methodology in knowing how to obtain informed consent clearly illustrated the need for academic publications to focus on this topic.¹³ As with IRB approval, although I had initially taken the process of consent for granted, it was one of primary importance and is one that other researchers will invariably encounter. I found that the Evaluation to Sign Consent Measure was the most palpable option for my use, but learned of its methodological issues upon administering it. The fact that I asked individuals with memory problems to answer questions based on a consent form they had read only minutes earlier was a glaring problem. Again, because of the exploratory nature of this research, it was my best option.

Difficulties in accessing the population taught me not to have an unrealistic inclusion criterion. I had initially planned only to interview community-dwelling, Caucasian women, aged 65 years and older who were in the early-stages of Alzheimer's disease, and could provide both legal and informed consent. Upon recruiting, I did not know that my population was largely non-existent. Obviously there were women with the disease that lived in their homes and could provide legal consent. According to my

¹³ Also called for by Dewing (2002).

consent measure, however, many of them were simply unable to provide informed consent.

Another impediment I faced in recruiting participants was due to the diagnostic process of the disease. Diagnoses of early-stage Alzheimer's disease is not as common as one might think, as both the person with memory problems and his or her attending physician often avoid the diagnosis until absolutely necessary. Individuals who are in the early-stages and do have the diagnosis often do not want to acknowledge it, and some are simply unable to due to the disease process.

I also realized that the different agencies through which I had been recruiting represented persons with Alzheimer's at completely different stages of the illness. For instance, the three diagnostic centers I had been convinced would have individuals willing to speak with me yielded no study participants. I learned through this that people are just starting to figure out what is wrong at these centers, which again indicates a lacking of the specified Alzheimer's diagnosis. It was also the case at one of these centers that caregivers were simply prohibiting access to the person with Alzheimer's.

Other agencies such as adult day cares have clients who have Alzheimer's, but these individuals have progressed in the disease process to a point at which a researcher using the ESC will simply not be able to obtain consent from that individual. One of the most helpful agencies in recruiting participants was one of the state chapters of the Alzheimer's Association. This organization provided referrals for four women in all, three of whom could provide consent. Two of the three participants had caregivers who had been involved in a support group.

An overall lesson learned while conducting this research was the importance of professionals and family caregivers while recruiting and interviewing participants. Most of the professionals with whom I came into contact were extremely helpful, facilitating and advocating for the research by passing the word along to others in the field who might know of potential respondents. Likewise, the majority of the family caregivers of potential participants were just as helpful, often scheduling the interviews and even being willing to be present the day of the interview in order to assist in conversations. Essentially, caregivers indeed are willing to participate in research and can be a valuable additional perspective for researchers to pursue.¹⁴

My contact with the IRB, the debate about how to determine consent and the navigation of professional and family gatekeepers all culminated the day of the interview when I was face-to-face with the person with Alzheimer's, asking her to describe her story. I knew that interviewing a person with Alzheimer's could pose a challenge and although I was aware of the interview techniques I would use, I was not fully equipped to completely understand my participants' experience. Upon transcribing the interviews, it was clear there were some questions I failed to ask when clearly being invited by the respondent to do so. There were other questions that I asked repeatedly, that I should have mentioned only once. This being said, I now realize that communication with a person with Alzheimer's is an art form that only gets developed with time and experience. An amateur in the field (such as myself) who has never formally interviewed

¹⁴ Also demonstrated by MacQuarrie (2005).

a person with the disease cannot expect to have honed his or her communication style in a way that most adequately elicits the sought after information. Quite simply, I did the best I could the day of the interview and went with it, even finding myself learning how to conduct a mock interview when the participant could not provide consent.¹⁵

Researchers also need to be aware that their reports might not be as uniform as they would like them to be. Participants might have offered answers that can not fit into the predetermined categories the researcher created prior to conducting the interview. In the present study, for instance, I had asked participants to define a good friend who was not a family member. One woman had named a dead person, being under the impression that the friend had just moved away. Another woman had named her niece because her network had decreased since being diagnosed, leaving her with no close friends. Lastly, one woman did not specifically name anyone and instead had spoken about her friendships in general. In this particular case, I do not believe the participant could have remembered if she actually had a good friend. These inconsistencies were all in some way connected to the person with Alzheimer's disease and made comparing across cases difficult.

Essentially, researchers pursuing the firsthand accounts of this population will need to be more critical of normally assumed situations and topics, such as the IRB and consent. One of the primary ways to encourage further study on this topic is for scholars to provide in-depth methodology sections in research studies. Although page or word

¹⁵ A mock interview involved engaging a participant in an in-depth conversation on the topic of friendship or any other topic she might find of interest, but not tape-recording any of dialogue we shared.

limits in journals might prevent scholars from reporting in a more detailed manner, quite simply, they still must write about how to do research with persons with Alzheimer's.

The reason the present study is not a mere substantial contribution is because of this lack of clear guidance in methods. In conclusion, this study illustrates a primary reason why researchers need to be concerned with pursuing these accounts and crossing the hurdles associated with surveying this population.¹⁶ Essentially persons with Alzheimer's are able to speak about the disease; indeed, this is a feasible way of conducting research.¹⁷

Specific Guidelines for Researchers Pursuing Firsthand Perspectives

As previously mentioned, researchers who want to pursue the firsthand views of persons with Alzheimer's will invariably encounter an IRB, will need to address the topic of informed consent and will negotiate with family and professional gatekeepers during the research process. Researchers should work in close contact with their IRBs and make them aware of the research goals as soon as possible because these kinds of studies will likely go to full review. Allowing caregivers to be present during interviews as well as using a capacity assessment to determine whether participants can provide consent can both strengthen the data and increase the chances of IRB approval. Researchers should be willing to modify the IRB application as many times as necessary in order to attain the projected sample size, whether it means continually adding new agencies for approval or widening the inclusion criteria to interview people with varying demographic characteristics. One way to increase the likelihood of obtaining an adequate sample size

¹⁶ As well as one conducted by MacQuarrie (2005).

¹⁷ Also supported by Clare (2003).

is to be willing to interview people with any form of dementia rather than only people with Alzheimer's.

While recruiting, researchers should contact as many professionals in the field of aging as possible and be willing to explain that persons with Alzheimer's can offer their perspectives. If sampling early-stage individuals, the researcher should not recruit at adult day centers but should rather focus on diagnostic centers, senior centers, and chapters of the Alzheimer's Association. While contacting professionals, researchers should be aware of the advantage these individuals provide in informing about the person with Alzheimer's situation. Likewise, family members and caregivers can inform about the person with Alzheimer's awareness of the disease and willingness to discuss the topic. Researchers should be open to having either a professional or family member present during the interview and need to realize the advantages of such.

The researcher should mandate the person with Alzheimer's be willing and able to discuss the diagnosis upon scheduling the interview, thereby making it easier to introduce the topic of Alzheimer's during the interview. In cases when the researcher has sampled individuals who are unaware of their diagnosis or are not willing to talk about it, the researcher should use another life event (as informed by the caregiver perhaps) as a reference point for the discussion. For instance, if the person with Alzheimer's relocated close to the time of being diagnosed, the researcher could ask a question like, "How has life changed since your move?"

Prior to beginning the interview, the researcher should read the person with Alzheimer's the consent form slowly or have him or her read it. After asking the

capacity assessment questions, the researcher simply needs to wait as long as necessary for the respondent to answer. The researcher should be willing to rephrase the question or ask it again, or even allow the respondent to read the capacity assessment again in order to answer questions correctly. If the participant does not have the capacity to provide informed consent, the researcher should ask the respondent questions as if conducting a formal interview, but should forgo tape-recording the conversation, thereby conducting a mock interview.

As previously mentioned, researchers should ask direct questions during the interview and use as few words as necessary. They should also speak to the person as if she or he is an adult, but slow down their speech in order to allow the person with Alzheimer's the time to process what is being discussed. The interview should not follow a rigid format as it will most likely go in varying directions. When a caregiver is present, if she or he starts to take over the interview, the researcher may politely say, "If I need to better understand something, I will let you know," and then focus attention again on the primary informant. A respectful but firm tone is imperative while doing this.

If a participant becomes emotionally distressed during an interview, the researcher should be willing to contact someone (a friend, family member, counselor, social worker, etc.) to help the person with his or her feelings. The researcher should also be willing to sit with the person as long as it takes, the entire day if need be, especially if interviewing the person without a caregiver present. Follow-up is another key to interviewing persons with Alzheimer's. The researcher should be willing to call and check-up on the person with Alzheimer's following the interview. Lastly, the researcher

might possibly inform a family member or professional gatekeeper if the person with Alzheimer's reacted negatively to the interview.

CHAPTER V

SUBSTANTIVE LITERATURE REVIEW

As previously mentioned, the purpose of this study was to examine the patterns that characterize the friendships between people with Alzheimer's disease and cognitively intact individuals. One of the primary reasons I undertook this study was because the research literature has little to say about these particular kinds of relationships. Another reason was that studies reporting the firsthand accounts of people with Alzheimer's disease are underrepresented in the research literature. Lastly, because friendships are of great significance for older adults, and are possibly even more significant for people with Alzheimer's, I thought it an appropriate and worthwhile topic to study.

This literature review begins by highlighting research that shows the importance of friendships and how they relate to older adults' self-esteem, selfhood, and well-being. The chapter then shifts from reviewing research on the general topic of older adult friendship to the research documenting the more specific topic of mixed friendships. The relevancy of the present study becomes evident in light of the background information about the importance of older adult friendships coupled with an outline of the patterns that characterize mixed friendships.

The primary question guiding this study was: what are the patterns that characterize mixed friendships? Again, a mixed friendship is one composed of a person

with Alzheimer's and a cognitively intact individual. At the time of this literature review, the studies surrounding this topic were scant in number. There was, however, enough literature to suggest areas I needed to explore while engaged in this inquiry and to offer ideas of what I might find. A set of informal hypotheses provide the conclusion for this chapter. Although these hypotheses are not testable, they are intended to guide this inquiry in an attempt to generate hypotheses for future studies.

The Significance of Older Adults' Friendships

Friendships are important to older adults, as friends play a crucial role in providing the social support that individuals need in coping with life's demands (Blieszner & Adams, 1992). Research shows that friendships are associated with older adults' self-esteem, selfhood, and well-being. The frequency of interaction with friends is positively related to their self-esteem in a way that interactions with family members are not (Lee & Shehan, 1989). When an older adult, or any individual for that matter, is chosen as a friend, it implies that there is something good about the individual chosen, that she or he has positive characteristics (Lee & Ishii-Kuntz, 1988). Not only does involvement in a friendship help increase the self-esteem of older adults, but it also helps them maintain their sense of identity, otherwise known as selfhood (Kitwood & Bredin, 1992; Van Dijkhuizen, Clare, & Pearce, 2006).

By remaining active in friendship relations, older adults are able to hold onto a stable self-concept, or sense of who they are as a person, whereby creating a buffer for themselves against the impact of stressful events (Lee & Shehan, 1989). Although at least one study (McKee, Harrison, & Lee, 1999) shows no link between older adult

friendship and well-being, the majority of research would indicate otherwise. Informal activity based on mutual choice, that is, friendship interaction, positively affects well-being for older adults and is associated with lower levels of loneliness and a higher morale in ways that family relationships are not (Lee & Ishii-Kuntz, 1988).

One might consider the scholastic inquiry of the topic of friendship as superfluous, however, as previously mentioned, the value of these relationships for older adults is clearly evident. Studies (i.e., Litwin & Shiovitz-Ezra, 2006; Sabin, 1993) in the general older adult population have shown the link between friendship and a reduced risk of mortality. For people with Alzheimer's disease, the importance of friendships might be even more pronounced, as those in the early to mid-stages often display fears of abandonment (Gwyther, 1997). This fear is clearly legitimate in that their cognitively intact friends do have a tendency to disengage, often resulting in isolation for the person with Alzheimer's (Cohen & Eisdorfer, 2001), a topic which I discuss later.

Mixed Friendship Patterns

Again, a mixed friendship involves an individual with Alzheimer's disease and a person who is cognitively intact. This section provides specific examples of thoughts, feelings and behaviors (interactive processes) typically occurring within these friendships followed by a discussion on the form of the ties linking friends together (internal structures) and is concluded with a focus on how these friendships change and evolve over time (friendship phases). This literature review is organized around these three concepts (process, structure, and phase) as a result of Blieszner & Adams' (1992) use of

them in their comprehensive analysis of the literature on adult friendship. These concepts helped organize the overall framework for the present study.

Thoughts, Feelings, and Behaviors Taking Place between Friends

The interactions occurring within mixed friendships can have potentially positive and negative effects for the person with Alzheimer's. As the following studies illustrate, the exchanges typically characteristic of these friendships, whether they are in the form of thoughts, feelings, or behaviors, are often negative. Unfortunately they not only threaten the friendship but also prove detrimental for the person with Alzheimer's.

Thoughts and Feelings

By at least being aware of the typical thought processes occurring between members of a mixed friendship, researchers can then start to understand the effects they might have on the relationship. Ultimately, the way persons with Alzheimer's and their cognitively intact friends think about one another can either foster the friendship's continuation or lead to its dissolution.

Monitoring of reciprocity. A typical thought process occurring within mixed friendships is the *monitoring of reciprocity*. This is the general record keeping that goes on between the dyad members regarding what they do for each other. As with other populations, individuals with Alzheimer's and their cognitively intact friends engage in this pattern in order to maintain a balanced level of "give" and "take" within the friendship (Chiriboga, 2001; Ficker, MacNeill, Bank, & Lichtenberg, 2002). The potential difficulty facing these friendships, however, is that they are more likely to develop and continue in imbalanced exchanges. The person with Alzheimer's might

simply require a higher amount of social support from the friend than can she or he can offer in return (Chiriboga, 2001). If the cognitively intact friend holds the perception that she or he is offering too much support to the person with Alzheimer's while receiving too little in return, she or he might react by becoming distant, or by choosing to end the friendship altogether. For this reason, in order to retain the friendship it becomes necessary for the friend to reframe his or her expectations of the person with Alzheimer's (Cotrell & Schulz, 1993).

Homophily. Another thought process occurring within mixed friendships involves the judgment of whether the friends are similar or not. *Homophily* is the tendency for friendships to form between those who are alike in some designated respect (Lazarsfeld & Merton, 1954) and is typically characteristic of older adult friendships (Blieszner & Adams, 1992; Gutheil, 1991). Older adults are willing to go to greater lengths to engage with those who are like themselves (Nahemow & Lawton, 1975) and in group settings, such as adult day centers, are more likely to gravitate toward others of the same functioning capacity (Williams & Roberts, 1995). The nature of a mixed friendship violates the norm of homophily in that the person with Alzheimer's and his or her friend are functioning at two different cognitive levels. The violation of this norm can threaten the continuation of this friendship that would not have been experienced if the friendship had been between two individuals with similar levels of cognitive capacity. Essentially, if either of the two friends were to perceive their differing capacities in a negative manner, the friendship could potentially dissolve.

Person-turned-patient mentality and excess disability. Although persons with Alzheimer's report not perceiving their illness as being their whole life or identity (Gwyther, 1997), cognitively intact friends do not always share this view. A negative thought process that characterizes mixed friendships occurs when the cognitively intact friend employs a *person-turned-patient mentality* toward the person with Alzheimer's. The friendship can easily become based on deficiencies (Sabat, 1994; 2002) when the cognitively intact friend attributes the experience of the person with Alzheimer's exclusively to a disease process (Cotrell & Schulz, 1993). Along the same lines, cognitively intact friends might start to speak of the person in past-tense, even though the person is a part of their present and might even perceive the person with Alzheimer's as a stranger (Corner & Bond, 2004).

Although possibly well-intending, if the cognitively intact friend inaccurately assesses his or her friend's capabilities, she or he may assume more responsibility than necessary, leading to a loss of autonomy for the person with Alzheimer's (Chiriboga, 2001). The cognitively intact friend's misjudgment combined with action can result in the person with Alzheimer's experiencing a social or "excess" disability in addition to the purely biological one. *Excess disability*, then, is a form of disability that is in no way related to the normal pathology of the disease but rather is the result of how the friend of the person with Alzheimer's perceives and treats him or her. When the cognitively intact friend misjudges the person with Alzheimer's capabilities and treats him or her in such a way that fails to maximize the use of his or her remaining abilities, the person with Alzheimer's will demonstrate a loss of ability (Sabat, 2002). When the person-turned-

patient mentality translates to action, it takes on the form of excess disability, resulting in negative outcomes for the person with Alzheimer's.

Stigma. In the context of mixed friendships, stigma is similar to excess disability in that it begins as a thought process and is usually followed by a behavior, subsequently resulting in an adverse situation for the person with Alzheimer's. These individuals often experience both *enacted* and *felt stigma* within their friendships (Cotrell & Schulz, 1993; Snyder, 2002). Felt stigma arises when the person with Alzheimer's thinks there is a reason to be ashamed of his or her illness. Enacted stigma arises when the cognitively intact friends of the person with Alzheimer's devalues or mistreats him or her based on their own fear and discomfort. It also occurs when cognitively intact friends discriminate against or reject the person with Alzheimer's as a result of the illness (Cotrell & Schulz, 1993; Snyder, 2002). Whether felt or enacted, there are a number of ways in which stigma can affect a mixed friendship. One such example regards whether the person with Alzheimer's even decides to disclose the diagnosis to his or her friend (Snyder, 2002).

Fears and anxieties. This section concludes with examples of feelings occurring within mixed friendships. Similar to thought processes, the feelings the friends have regarding each other or the friendship can also pose as threats to the relationship's continuation. As previously mentioned, persons with Alzheimer's have a legitimate fear of being abandoned (Gwyther, 1997). On the opposing side, cognitively intact friends often fear developing the disease themselves, leading them to be less likely to visit the person with Alzheimer's (Corner & Bond, 2004). If not dealt with, these fears can have negative consequences for the friendship, and can potentially lead to its dissolution.

As mentioned at the beginning of this section, it is of value to understand the thoughts and feelings occurring between persons with Alzheimer's and their cognitively intact friends. In doing this, researchers can then see how such processes can either help sustain such friendships or cause them to end. Whether a thought, way of thinking, or a feeling, each of the examples previously described have one common thread, and that is they are all potential threats to mixed friendships.

Taken together, the negative thoughts and feelings occurring between the dyad members are often detrimental not only to the friendship but also to the person with Alzheimer's on an individual level. For someone with the disease, being involved in relationships that are grounded in the constant awareness of his or her illness-related deficits can result in a loss of energy and interest in life. Depression among these individuals is more likely to be connected to the treatment of others rather than the actual decline of their cognitive abilities (Cotrell & Schulz, 1993). The "aspects of a person, the socially presented persona can be lost, but such losses are not direct effects of Alzheimer's disease, but are more directly related to the ways in which the person with Alzheimer's disease is treated healthily by others" (Sabat, 2002, p. 90). In other words, a cognitively intact friends' treatment of the person with Alzheimer's can have health implications for the person with the disease.

Behaviors

Scholars need to be aware not only of thoughts and feelings occurring between persons with Alzheimer's and their cognitively intact friends but also must be able to examine the behavioral processes that characterize these friendships. In doing so, the

research community can then begin to speculate as to how behavioral processes might contribute to the friendship's continuation or dissolution.

Communication. Although communication is a behavior typically taken for granted within a friendship, communicating is a challenge that dyad members of a mixed friendship will invariably have to meet. With the progression of the disease, communication behaviors will inevitably change for the person with Alzheimer's (Ficker et al., 2002). The lapses in memory affecting his or her train of thought and the subsequent inability to follow a conversation can result in the individual being less comfortable speaking with a cognitively intact friend (Clare, 2002; Phinney, 1998). Managing the demands of the social situation with a friend can become difficult, as the person might feel the need to compensate for or hide memory problems.

Simply trying to remember a friend's name can prove nearly impossible, as conversation becomes like an art, with the person with Alzheimer's often losing the ability to find the "right" words (Clare, 2002). As the disease process begins to change the individual's previously held pattern of communicating, she or he might have the desire to avoid communication with cognitively intact friends altogether. The changes in communication behaviors within mixed friendships can prove a threat to these friendships, whereby affecting the dyad members' ability to sustain such relationships (Ficker et al., 2002).

Companionship. As with communication, companionship is another friendship process that members of mixed friendships cannot take for granted. Even though the companionship offered by a friend is important for older adults (Gutheil, 1991), it often is

not a reality for the person with Alzheimer's (Clare, 2002). Persons with Alzheimer's routinely lack the companionship of others sharing the same experience which sometimes results in a lack of the opportunity to discuss the disease openly (Clare, 2002). Although communication about the disease within the friendship is a necessity, especially in the early stages of the illness (Clare, 2002), there is often closed communication within these friendships (Van Dijkhuizen et al., 2006). The lack of companionship and open communication is a topic which members of a mixed friendship need to discuss in order to promote the continuation of their friendship.

Social support. Although friends are a primary source of social support for older adults (Chiriboga, 2001; Gutheil, 1991), cognitively impaired individuals hold the perception of having lower levels of support than cognitively intact individuals (Ficker et al., 2002). For the person with Alzheimer's, the social support provided by a cognitively intact friend can help prevent depression (Blazer, 2005), as isolation and lower levels of support are related to depressive symptoms (Blazer, 2005; Bruce, 2002; Chi & Chou, 2001). In order to aid in sustaining the friendship, the cognitively intact friend must be willing to provide the person with Alzheimer's the social support she or he will likely be in need of.

Role reformation. Along the lines of providing each other social support, members of mixed friendships need to reform their respective "friendship roles", or what they expect from one another. Persons with Alzheimer's might need help in remembering such things as their friend's name or in remembering what time lunch is, and in this way they might start to rely on the cognitively intact friend to "fill in the gaps"

(Phinney, 1998). Oftentimes, the cognitively intact friend will offer help and support if the person with Alzheimer's proves not to be "too needy" (Gutheil, 1991). The significance of role reformation in the context of a mixed friendship regards both dyad members having an understanding of what to expect from each other to prevent both from feeling taken advantage of by the other.

In summary, individuals involved in a mixed friendship will no longer be able to take for granted the routine behaviors of communication, companionship, and social support. The person with Alzheimer's and his or her cognitively intact friend will need to address such issues as well as think about how each individuals' roles might be reformed within the friendship in order maintain a friendship they actually desire to be a part of.

The Form of the Ties Linking the Friends

The previous section examined a number of friendship processes ranging from the ways in which persons with Alzheimer's and their cognitively intact friends think and feel about one other to the different kinds of things they do together and for each other. After outlining such processes, the majority of which are not favorable for the person with Alzheimer's, it is fitting to report on the structural characteristics of these friendships. This section discusses the solidarity experienced within mixed friendships as well as the size of the person with Alzheimer's friendship network.

Solidarity

Not only can Alzheimer's disease affect what takes place in a mixed friendship but it can also affect how the friends are connected with each other as well. As his or her cognitive skills decline, maintaining the friendship can become problematic for the

person with Alzheimer's. The solidarity within the friendship decreases as each individual becomes more distant, often as a result of the person with Alzheimer's receiving less assistance from his or her cognitively intact friend. Some individuals with cognitive impairment (not solely Alzheimer's disease) hold the perception that friendships are less supportive for them versus cognitively intact individuals (Ficker et al., 2002). In summation, the person with Alzheimer's illness combined with his or her friend's reaction to it can threaten the friendship's level of solidarity.

Size of Network

The majority of this review has focused on mixed friendships on a dyadic level; that is, examining only one friendship rather than multiple ones. This section, however, concentrates on the person with Alzheimer's entire friendship network. The following examples are illustrative of how the negative reactions of others based on his or her illness can affect the individual's number of friends overall.

Researchers have portrayed persons with Alzheimer's disease as being tucked away at the margins of society (Corner & Bond, 2004), describing Alzheimer's as a disease of exclusion (Gubrium, 1986). For persons with Alzheimer's, the world becomes narrower, as their friendship networks starts to shrink and they become more socially isolated (Clare, 2002; Corner & Bond, 2004; Phinney, 1998; Snyder, 2002). Researchers attribute the friendship network's breakdown to the stigma accompanying the disease as well as to the discomfort cognitively intact friends might experience while interacting with the person with Alzheimer's (Corner & Bond, 2004).

The relinquishment of social activities can also affect the size of the person with Alzheimer's friendship network, which sometimes happens when she or he is unable to participate in a manner as in previous times. Another common reason for the decrease in the person with Alzheimer's number of friends is because of the lack of reciprocity within the friendships (Cotrell & Schulz, 1993).

When their friendship networks starts to shrink, persons with Alzheimer's often experience internal feelings of isolation. As one woman with the disease described: "You're so alone with it. Nobody around you knows what is going on" (Snyder, 2002, p. 126). Unfortunately, these individuals are often left with the task of seeking out people who have avoided them (Corner & Bond, 2004) at a time when it is of great importance for them to preserve their social selves (Clare, 2002; Phinney, 1998; Snyder, 2002). The effects of the disease are more difficult for the person with Alzheimer's to fight back against when she or he is isolated from his or her friends (Clare, 2002).

In conclusion, the cognitively intact friend's negative reaction to the person's disease can impact the mixed friendship by decreasing the friendship's level of solidarity. Friends' negative reactions can also translate into a network level change by causing it to shrink and eventually disappear altogether. Regardless of whether there is a change in just one friendship as a result of his or her disease or whether his or her entire friendship network changes, such situations are normally unfavorable for the person with Alzheimer's.

How Friendships Change and Evolve Over Time

The previous sections focused on the thoughts, feelings, and behaviors that typically characterize the friendships of persons with Alzheimer's and cognitively intact individuals. They also examined the ties connecting the friends by concentrating on the solidarity within mixed friendships as well as the size of the person with Alzheimer's friendship network. This discussion concludes with an investigation of the how the friendships are sustained through time, how they commonly dissolve, and how new ones begin.

Sustainment

In light of the difficulties persons with Alzheimer's face in social functioning, the stigma surrounding the disease, and the often unhelpful reactions coming from well-meaning friends, it is completely plausible to believe that these individuals would have a natural tendency to disengage from their friendships. It is often the case, however, that they go out of their way to sustain friendships in an effort to remain as normal as possible, attempting to live as they did before they were diagnosed (Phinney, 1998). These individuals are able to maintain a sense of continuity and whereby minimize the impact of their illness by attempting to remember the names of friends and by continuing to stay socially engaged (Phinney, 1998).

For the friendships that are sustained throughout the course of the illness, the person with Alzheimer's and his or her cognitively intact friend need to learn how to balance a sense of realism versus optimism in order for the relationship to be a healthy one (Clare, 2002; Yale, 1999). This will require both parties to learn how to remain

positive while simultaneously rising to the challenge of dealing with a degenerative disease. Cognitively intact friends will carry the responsibility of balancing the reality of the illness and its progression with being cognizant that there is a person behind the illness (Goldsmith, 1996).

Dissolution

Unfortunately, however, it is commonly the case that persons with Alzheimer's and their cognitively intact friends are unable to sustain their friendships. The cognitive decline associated with the disease routinely leads to a loss of support from friends, oftentimes leading to the dissolution of friendships for the person with Alzheimer's (Aartsen, Van Tilburg, Smits, & Knipscheer, 2004). Cognitively intact friends often distance themselves from the individual for the purposes of self-protection, making the loss for the person with Alzheimer's even more pronounced (Goldsmith, 1996).

Generally speaking, friendships are more fragile than are other social relationships due to their lack of formal constraints and basis of reciprocity without obligation (Adams, 2001; Ficker et al., 2002). This lack of obligation has implications within a mixed friendship that otherwise would not be experienced if both parties were cognitively intact. The difficulties a mixed friendship faces combined with the non-obligatory nature of a friendship can heighten the likelihood of the friendship's dissolution.

Initiation

The situation of persons with Alzheimer's as it relates to their friendship networks is not completely discouraging, however, in that there is hope for the formation of new

friendships after they have been diagnosed. The loss of cognitive abilities and “normal” communication skills does not completely prevent the person with Alzheimer’s from developing social ties (Williams & Roberts, 1995). In fact, physical and cognitive impairments can actually encourage the initiation of friendships through a bond of caregiving (McKee et al., 1999). Even after the onset of their disease, if given the opportunity, persons with Alzheimer’s are still able to enrich others’ lives through social interaction. New friendships can develop out of the dyad members’ mutual need, shared activities and interests, and common patterns of behavior (Williams & Roberts, 1995).

Summary

To conclude, this chapter has reviewed literature demonstrating that friendships are significant for older adults, often acting as facilitators of self-esteem, well-being, and selfhood (Blazer, 2005; Chiriboga, 2001; Downs, 1997; Ficker et al., 2002; Lee & Shehan, 1989; Van Dijkhuizen et al., 2006). This review has also shown the importance of friendships for individuals with Alzheimer’s disease and has outlined research documenting the patterns of mixed friendships. By reviewing studies that report the thoughts, feelings, and behaviors occurring within the friendships, the form of the ties linking the friends, and the changes and evolution of the friendships, I have generated a set of informal hypotheses regarding this topic which follow. These ideas are a guide for this exploration of mixed friendship patterns.

General Ideas about Mixed Friendship Patterns

Again, the primary question I posed in the present study was: what are the patterns that characterize mixed friendships? Guided by the existing literature, I expected to find the following patterns within such relationships:

- An imbalance of social support, with the person with Alzheimer's more frequently finding herself in the position of a support receiver.
- The realization between the friends that they are now "different" on account of the person with Alzheimer's change in cognitive functioning capacity.
- Negative processes such as a person-turned-patient mentality, excess disability, and stigma, all resulting in negative outcomes for the person with Alzheimer's.
- Fears and anxieties experienced on behalf of both the person with Alzheimer's and her cognitively intact friend pertaining to the friendship.
- Communication challenges experienced by the person with Alzheimer's while interacting with her friend.
- The lack of companionship and open dialogue as experienced by the person with Alzheimer's surrounding her illness experience.
- Role reformation to take place between the friends causing them to re-examine their expectations of each other.
- The decrease of solidarity between the person with Alzheimer's and her friend.

- The gradual shrinkage of the friendship network of the person with Alzheimer's eventually resulting in her social isolation.
- A balance of realism versus optimism for the person with Alzheimer's and her cognitively intact friend.
- The cumulative effects of the negative thoughts, feelings, and behaviors exchanged within the friendship of the person with Alzheimer's and her cognitively intact friend to result in the dissolution of the friendship.
- The formation of potentially enriching new friendships for the person with Alzheimer's post-diagnosis.

As previously mentioned, these are general ideas and not formally testable hypotheses.

They are, however, intended to guide this research project in an endeavor to report on the friendship patterns of persons with Alzheimer's disease and cognitively intact individuals. The following chapter provides a description of the findings of the present study.

CHAPTER VI

SUBSTANTIVE RESULTS

Introduction

This chapter provides the firsthand accounts of the women I interviewed in this investigation of mixed friendship patterns. The chapter begins with each woman's story presented as a case study, after which I compare the similarities and differences between each respondent's friendship patterns. The themes that emerged during data analysis include factors acting to facilitate and constrain friendships, fulfilled versus unfulfilled friendship aspirations, and a sense of continuity throughout the respondents' lives, the discussion of which provides the latter half of this chapter. I have changed all of the names throughout the rest of this paper in order to protect the respondents' anonymity.

Case Studies

Irene

Irene was an 83 year old Michigan native who had been living in North Carolina for thirty years. She and her husband of twenty years, Walter, lived in a small town. This was her third marriage and his second. Irene had been diagnosed with Alzheimer's disease for three years.

Although having lived in the same community since her move three decades prior, she still was not fully integrated in the group of church friends that had lived there all their lives. Irene more or less occupied a periphery position among these women;

an outsider looking in. Regardless, she considered them to be her primary group of friends. Irene found herself closest to another woman who like her, was not as close to the others. Mildred also was from another town and like Irene, seemed to prefer spending time with her husband as opposed to with this particular group of women. Irene and Mildred's friendship had spanned over twenty years. The two shared a lot together, as they were part of the same church and with their husbands had traveled all over the United States. The two couples had gone on a five-week trip across country years back, and were still on speaking terms upon returning.

In Irene's opinion, Mildred was a lovely person and a good friend, one with whom she had never really experienced any problems. Mildred did, however, have a tendency to gossip. "I have always been careful [of] what I say with her, but she's, she's a very good friend." Irene simply knew to avoid discussing anything with Mildred that she wanted to keep private.

Irene, though, had always been one to keep things to herself. Her career was as a registered nurse, an occupation for which she was trained to listen to others. Her delicately tuned listening skills combined with her preference to remain private might have accounted for the reason why she did not discuss her disease with Mildred, or any of her other friends for that matter. When asked whether Mildred knew about her disease, Irene replied, "I would imagine she does. I've never, we've never talked about it, but she knows that I don't remember things well...I've always been a, well I keep a lot of things to myself. I always have." Although they never openly discussed it, Irene suspected that

when her disease progressed, Mildred would accept her like she was. “I know that I think she would hang in there.”

Irene and Mildred normally shared dinner together with their husbands on Friday nights and would occasionally take in a concert afterwards. As in times past, trips to the beach were still made with regularity as the two couples continued to enjoy each other’s company. Generally speaking, Irene liked the amount of contact they had with each other and preferred it to remain at that level. Although she did not depend on Mildred for anything, she expected that if the need were there, her friend would rise to the occasion.

Irene was still just as involved in her church as she had been in previous years, attending Sunday school and sharing weekly fellowship dinners with a group of twenty or more other church members. Her attendance at such gatherings was now primarily for her husband’s benefit rather than her own. Because of the Alzheimer’s, Irene now found it difficult to follow a conversation or to recall a person’s name she would have easily remembered in times past. “If they [friends] want to talk about what’s in the newspaper, even if I’ve read it I can’t pull it back up again. Things, just are blank, and uh, I would go out but I would feel, I would feel left out, because I don’t know, I can’t get into the conversation. And they don’t mean it, you know, and I realize that. But it’s embarrassing.” Her frequent confusion was a source of shame for her because she was now different from others. As a result, Irene found herself relying on her previously honed listening skills for survival in social situations in an attempt to spare herself embarrassment.

Irene preferred to avoid being around others where her communication challenges would be most evident. “I’d rather stay home. I’m alright with the family, I mean, they don’t make it...they just say, ‘look, it was this or that or the other thing mom.” She recognized that she was starting to withdraw with her increasing desire to stay at home. Although she did like people, Irene simply was not interested in making new friends. She balanced her desire to disengage against her husband’s need for contact with others. For her, Walter’s needs weighed more heavily, which caused the reality of her situation to be in clear contrast to what she would have actually preferred. “I’d rather just stay home. I’m not comfortable being with other people because I’m different <tearing up>... We don’t stay home. My husband has a right to visit with his friends and he needs that. Because pretty much he stays pretty close to me so he’s seeming a bit confined perhaps. And that bothers me <tearing up>.” Despite her desire to do otherwise, Irene continued her social engagement with friends and fellow church members being ever mindful of her husband’s needs.

Irene was now occupying unknown territory in the position of a care-receiver, as she had always been the one to be the caregiver. In this way, Walter was her rock and their relationship was of the utmost importance to her. Irene was ever-conscious of what her husband was experiencing, allowing his direction in guiding their social involvement. Walter was carrying out the doctor’s orders by keeping her socially engaged, resulting in their participation in every church function and social gathering they could attend.

Irene was having a tough time in regards to her disease, as she had just been recently accepting that she had a problem. As is typical of Alzheimer’s disease, Irene’s

problems were not physical in nature because she was up and about. Her difficulties in remembering caused her frustration and anger. She knew that she was forgetting and was unable to do anything about it. Ironically enough, the one thing she could not forget was that she had Alzheimer's. Her attitude, however, was somewhat optimistic. "My life has changed and I can't stop it. It just is out of my hands. I don't want to be this way, but I'll try to be the best I can." She thought herself fortunate in every way aside from having Alzheimer's disease.

Irene's suggestions to other persons with Alzheimer's were simple. Do not feel sorry for yourself, do the best you can and pray for patience. Her advice to friends of persons with Alzheimer's was of a similar thread, as she recommended patience, prayer and a positive attitude. "Take them like they are. They can't help it. And, if you feel like they need a little more attention, or if you feel like they'd rather be alone, be sensitive to that. And don't ask them to build a monument, or anything <chuckling>." To her, acceptance and sensitivity to the person's needs was highly important.

Ruth

Ruth was an eighty year old who had lived her entire life in the same small Virginia town right above the North Carolina border. Following her husband's death, she had moved in with her only child, a daughter with whom she had lived the past seven years. Ruth had been diagnosed with Alzheimer's disease for six years.

In her younger days, Ruth's primary work was in a doctor's office. She had many friends in her previous community with whom she participated in things like church activities, shopping and going to the movies. Ruth was an outgoing individual who found

it easy to talk to people. She thoroughly enjoyed laughing and having fun. Generally speaking, Ruth was not a private person and thought it fine to talk about anything.

Ruth's move to North Carolina drastically changed the amount of friends she had. Quite simply, she no longer had many friends. She wanted to continue in her former friendships, however, most of her old friends were busy with their own lives. Her daughter Sharon recognized that she was in need of a friend and introduced her to a woman named Doris. As it were, Doris was the mother of Sharon's best friend.

Ruth and Doris instantly hit it off. The two were similar, not just in age, but also in their capacity for a good time. "Oh it was wonderful. We'd go places and we'd have the best time, just two silly old women, and we'd go to lunch and we'd go to the movies, and we'd go to the shopping center, and we had the best time in the world." Whether they were having a hamburger out in town, watching the ducks down by the lake or were spending time at Ruth's house, they thoroughly enjoyed each other's company. "It seemed that everything we did we'd end up laughing like two idiots. I mean it was just fun with her." Ruth and Doris provided each other a source of fun companionship in their later years.

Ruth had no problems with talking to Doris about her disease but she also had never been one to shy away from talk of any kind either. "I was comfortable telling her or anybody, because it's just, that's just the way it is. That's just the way I would have had." Whether she had a doctor's appointment or was on a new medication, Ruth's friend kept right in touch with her disease and treated her no differently for having it.

Ruth and Doris' friendship spanned close to four years in length until death separated the two. Ruth was considerably grieved upon her friend's death. "It hurt me, terribly. It really did. And I missed her so much, you know. Because we really did have a good time together...Sometimes you're with somebody and it's just okay, but not special. But she was special and we just enjoyed each other so much. I don't think we ever got grumbly at each other, or anything at all. She was a doll in person." Ruth highly valued her friendship with Doris because of the enjoyment they shared together at an old age. Ruth wished she were still alive, because quite simply, she had not engaged in another friendship like their's since.

Ruth had been attending church and as a result met a younger woman whom she could consider a friend. The two of them did not have much in common because her friend had family responsibilities to deal with, whereas Ruth did not. She would like to have made new friends, but did not find it an easy thing to do because of her age. "It would be nice to have a friend like I used to but I just accepted that they're old and a lot of them have died, but this is just a way, this is life." Furthermore, old people did not seem to have the desire to do much of anything. For reasons such as these, she had very few friends in general and no one that she could identify as a close friend. Things were certainly not like they had been in former times. But that was okay to her.

Because of her tendency to be an extrovert, Ruth had no problems sharing with others what was going on in her life. This translated into a willingness to discuss her disease with anyone with whom she might come into contact. "I'd rather people know because I don't know that I will always say the right thing or do the right thing with

Alzheimer's." Ruth was not embarrassed about her illness at all. She would have told anyone she had Alzheimer's disease and felt completely comfortable doing so. "It's nothing to be ashamed of. It's just like having measles or breaking a leg or whatever, I have Alzheimer's, and a lot of people have it. And no, I'm not ashamed of it, it's just something that happens, and I happened to get it."

Ruth was thankful that she did not have Alzheimer's when she was younger. "When I first found out I had it, it's kind of a jolt to you, you know. But then, it's like you just get used to it, and then, you have to accept it. And I think I did a good job of it. And I just feel that if I make a goof-up, so what? The world's not going to stop turning. And you know, so I really don't worry about it." True, she got frustrated at times, but she also knew that she was doing the best she could. Ruth simply accepted that she had the disease and tried not to fight it. Overall, she thought she lived with it very well. "It is what it is."

Ruth was content with her life and although things were not like they once had been, she did not mind. She would have liked to make new friends but did not find it an easy thing to do because of her age. Ruth was content with her life, however, the way it was. Her days consisted of walking the dog in the morning, keeping house during the day and enjoying dinner with her daughter at night.

When offering suggestions for other persons with Alzheimer's, Ruth mentioned not allowing the disease to stop them. Continue in the same patterns you always have and when it is time to make a change, you will know. Her advice to friends of individuals with the disease was similar in that they should not change either. "Continue

to be the friend that you've always been. She's the one that's changing. See I'm changing, and like you're not. But if you were my friend, you should just keep, keep doing what you're doing. Take me to lunch, buy me a hamburger, or do whatever. But see, I'm the one that's changing, the one with Alzheimer's. And I think that they, they wouldn't change."

Carol

Carol was native of Pennsylvania and had grown up in one of its larger cities. After living in Connecticut, she moved to North Carolina at her daughter's urging between one and two years earlier. She lived with her son, whom she had just helped through a divorce. Carol was 68 years old and had Alzheimer's disease.

In her earlier years, Carol had been a woman in a man's world, as evidenced by winning the Man of the Year award at her college during a time when it was only awarded to men. She had led a career as a registered financial advisor and had traveled extensively appearing as a guest on radio call-in shows, discussing a variety of taboo topics from incest and rape to other forms of abuse. Her tendency to discuss issues openly that others would normally keep hidden might have been fostered by her familiarity with the mental health system. She had personal experience with mental illness, having once admitted herself into a psychiatric institution.

As a result of her various speaking engagements, Carol had an extensive friendship network that spanned many states. "It's nice to just be able to go to just about any town in the country and have friends. Somebody to talk to, somebody to eat dinner with." Although she had many friends, she did not have a best friend for the simple

reason that she did not want to eliminate anyone. Carol's friends were important to her because not only did they offer her respect, but they were honest with her as well. She thought her friends were great people and wanted to continue to make new ones for the purpose of not being alone. "I don't want to be isolated...Life would be boring. I want to do things."

Carol started attending the local Senior Center after coming to live with her son. At the Center, she was able to share many activities with her friends on a daily basis. They would play dominoes together, eat lunch and socialize, whereby providing each other a source of companionship. If one of these friends was going through a difficult situation, Carol would draw on her own life experiences, of which she had many, in an attempt to help the person in need.

Carol's desire to help people caused her to discuss topics openly that people did not want to talk about, including Alzheimer's disease. She was not one to keep her disease a secret and was willing to answer questions from friends who wanted to discuss it. For her, having Alzheimer's could be boring, but it never was. People wanted to have someone with whom they could talk about it. "I would assume that a lot of the people here [at the Senior Center] would love to sit in a room and talk about it and not have to feel guilty and it's perfectly alright to talk about it, and people should be talking about it." As was her nature, Carol was one to offer a listening ear to those who needed it while providing any advice of her own that could be beneficial to others.

For the most part, however, Carol did not think about her disease. She considered her future to be beautiful and was not scared of it at all. "It can only get better."

Her suggestions to the friends of persons with Alzheimer's were twofold. Simply, smile and listen without repeating. Gossip should not be included.

Diane

Diane was a proud Southern native who had lived in her small coastal town for the past ten years. She had shared a life with her husband, and with him had raised three children. Diane was 61 years old and had been diagnosed with Alzheimer's disease for two and a half years.

Diane had spent her career days as an office manager of a busy dental practice in her former community. When she moved after retiring, she left her old friends behind and made new ones through church involvement and playing tennis. Diane ranked relationships as being number one in her life other than spiritual matters. At previous points in life she could count many friends, but she no longer found that to be the case. "I was always an extrovert, a lot of friends. I have a smaller circle now."

Although she was still involved at her church and continued to play tennis, Diane no longer could identify a close friend who was not a family member. Her niece Laura had become her closest friend. "I don't know that we could love each other any more. Whatever capacity there is to love on this earth, and we're limited, because we're human, I think we're bonded that close." Diane and Laura had bonded over difficult family situations and had provided one another a source of support. Their relationship compensated for what both of them were lacking in their own mother-daughter relationships, as they each considered themselves to be the surrogate of what the other

needed. The two were simply able to talk and relate freely with each other about things that they could not share with others.

Diane's friendship with Laura offered a safe place to talk about her illness. Laura had an understanding of the disease that others might not because of her nursing background. If Diane did something that seemed strange or ever had a mishap because of the Alzheimer's, she had no need to worry because Laura would not judge her. When she had difficulties in communicating, Diane could rely on Laura to provide her with words that she might not otherwise have. There were also times, however, when Diane did not necessarily need help with communicating but could rely on Laura for it anyway. Regardless, Laura simply had the ability to express what she herself was thinking or feeling.

Diane's niece accepted her, allowing her to be comfortable. "She's one of the few people that I can say that I can totally be myself around...much more so than my children." Even though they were so close, it was refreshing that Laura still answered with a 'yes ma'am' during conversations. To Diane, this implied a level of respect that was characteristic of the southern culture, a culture which she was deeply fond of. In her opinion, Laura was not only brilliant, but also kind. Diane simply could not have thought more highly of anyone.

Diane and Laura had an intense bond despite miles apart and infrequent contact. To see each other would mean a trip of at least three hours by car, which resulted in them having face to face contact perhaps twice a year. The two did not phone frequently either. It did not seem to matter, however, because they both knew that if they ever

needed each other, they would be there. This simple awareness brought Diane a measure of comfort. Again showing how highly she valued their relationship, Diane did not want to imagine her life without Laura in it.

Diane did not have the same level of comfort around others as she had with her niece. The fear of making a blunder in a social setting is what kept her from continuing to stay engaged with friends. “I don’t go out and attend the social gatherings that I used to, so therefore that limits my social life. And I’m scheduled to go some place and absolutely determined that I’m going to go, but at the last minute I won’t go. The anxiety of it just, the fear overtakes me and I don’t go.” Diane realized that her network was shrinking. She had the desire to continue friendships, but her fear of making a mistake while interacting with others prevented her from doing so.

Diane had, however made friends with women who were employed with the Alzheimer’s Association. “When I am with the ladies from Raleigh, I feel one-hundred percent safe. They’re not going to embarrass me. They’re not going to let me embarrass myself for very long, they’ll get me out of the situation. Because they know. They know better than I know about what’s going on. So I can feel totally at ease in their presence.” Like her niece, these women knew something about the disease, which enabled her to be comfortable while in their presence.

Although she did share her diagnosis with a few friends, she had stopped being as willing to do so in more recent times. “I don’t go around announcing it...I could have at first...it didn’t feel real...I’m not that bad off. I’m not like I feel some other people, so why not? Well, I found out why not. It’s, it’s the stigma.” Diane was well aware of the

stigma associated with her disease and as a result would rather be around safe people, like Laura for instance, or her husband.

Diane's husband, Thomas, was willing to help her in any way he could. Diane was completely comfortable around him because of his patience and understanding. Because they were essentially a part of each other, a bad day for her would translate into a bad day for him. "He takes the ride with me." Diane had nothing to hide around Thomas and as a result found herself more likely to spend time alone with him rather than out with friends.

Diane knew that she was now a different person than in times past and attributed the change to Alzheimer's disease. Where she had previously been an extrovert who was willing to do anything, she was now more fearful. She formerly had a large network of friends, but now found herself lonely more often. Having Alzheimer's disease had radically changed her life.

In her advice to others with the disease, she suggested being aware of the importance of friends. "Appreciate them. It's the most valuable thing you'll have...It's lonely, it's lonely. Cause you need friends. You don't need a whole lot, but you really do need friends." In the same token, Diane advised friends of people with the disease to push through the walls they might erect. "Get in that raft and ride it with them...React and go with it. Whatever you have to do to ride with it." People with the disease are uncertain what is happening in their lives, but could certainly use a partner in the ride. In doing whatever it takes to relate, a good friend can be such a partner.

Similarities and Differences Between Cases

Although I fulfilled one research goal by reporting the firsthand perspectives of persons with Alzheimer's, I also answered the initial research question and did that by comparing the similarities and differences among the experiences of the four respondents. This analysis composes the following section. Tables 2 and 3 describe the respondent's social situations and characteristics of their friendships.

Table 2
Respondents' Social Situations

<i>Irene</i>
Lived with husband, relied primarily on him for support Occupation was as a nurse Private individual who kept to herself Still engaged in friendship network for husband's benefit
<i>Ruth</i>
Lived with daughter, relied primarily on her for support Formerly worked in a doctor's office Extroverted individual who did not keep things private Not engaged in friendship network since move seven years prior
<i>Carol</i>
Lived with son, unclear on whom she primarily relied for support Occupation was as a financial advisor Extroverted individual who did not keep things private Engaged in a friendship network with other Senior Center attendees
<i>Diane</i>
Lived with husband, relied primarily on him for support Occupation was as an office manager of a dental practice Extroverted individual who learned to be guarded about her disease Not engaged in friendship network despite friends having pursued her Participated much less in social activities than in former times

Table 3
Respondents' Good Friendships

<i>Irene & Mildred</i>
20+ year friendship Saw each other between once and twice a week Mildred liked to gossip Irene & her husband were compatible with Mildred & hers Irene could rely on Mildred if she needed Irene & Mildred did not discuss the disease
<i>Ruth & Doris</i>
3-4 year friendship Ruth's daughter had introduced them Ruth & Doris had fun with each other Doris had died Ruth & Doris discussed the disease
<i>Carol & friends</i>
Carol did not name a good friend Carol saw her Senior Center friends almost every day Carol's friends were of all ages Carol was willing to discuss her disease with her friends
<i>Diane & Laura</i>
Laura was Diane's niece They had bonded through other difficult situations They communicated at most four times a year Laura's nursing background helped her understand Alzheimer's An at least 20 year age difference separated the two Diane could rely on Laura if she needed Diane & Laura discussed the disease

An imbalance of social support, with the person with Alzheimer's more frequently finding herself in the position of a support receiver:

Irene, Ruth, and Diane's friendships with their good friend were all relatively equal in support exchange. These women did not depend on their good friend for much at all. Irene and Diane explicitly stated, however, that if they needed support, it would be there. Both of these women relied on their husbands primarily for assistance. Diane did find herself allowing her friend to verbalize things for which she would have not needed help before. In that way, the support her friend provided had somewhat increased, but the two still engaged in a relatively balanced relationship.

Irene, Ruth, and Diane also mentioned their friends initiating more contact than they did in return. Irene's friend contacted her far more frequently just to check up on her. Ruth's new friend who was younger initiated contact in their relationship as well. Lastly, Diane referred to her friends being the ones to sustain the friendship whereas she was not contributing as much.

Although Carol did not speak of one good friend in particular, she did mention that she and her friends would contact each other an equal amount. Like Irene and Diane, she mentioned that were she to need anything, they would be there to talk. Generally speaking, there were no differences between the women in that the level of social support they exchanged between friends was relatively balanced. The respondents and their friends primarily provided emotional support versus more tangible forms of support and all anticipated support were it to be needed (with the exception of Ruth, whose friend had died).

The realization between the friends that they are now "different" on account of the person with Alzheimer's change in cognitive functioning capacity:

The respondents demonstrated differing levels of awareness of their cognitive impairment in the context of their friendships. Because I only interviewed the person with Alzheimer's, I could not measure whether the friend perceived these differences as well. Irene clearly realized that she was different from others in social settings because of her inability to put things together like she once could. Diane, as well knew that she was different from her friends because of her disease, like for instance the women employed with the Alzheimer's Association. For her, these were comfortable

friendships because even though they did not have the disease, the women were well-informed about it.

Ruth did not explicitly mention being different from her friend because of her disease. She did, however know that her friend accepted her even though she had Alzheimer's. When she was out in public as well, she would mention her disease to others. In that way Ruth was disclosing her difference so that others who were unlike her would not think she was strange.

Unlike Irene, Ruth, and Diane, Carol did not acknowledge her differences in cognitive functioning. She did recognize that she had Alzheimer's disease, but never alluded to being different from her friends. Carol was also, however, the one to speak the least about her disease and seemed to demonstrate the least amount of awareness regarding it, which might have explained this difference.

Negative processes such as a person-turned-patient mentality, excess disability, and stigma, all resulting in negative outcomes for the person with Alzheimer's:

There was a general lack of negative processes on the dyadic level between the respondents and their good friend. The women Irene, Ruth and Diane had identified as a good friend seemed to think of them as a person rather than a patient. None of their friends treated them differently for having Alzheimer's disease. Irene's friend never mentioned her disease. Ruth and her friend were able to discuss the disease but despite that were also able to have fun together. Although Diane's friend was a nurse, she still treated Diane with the utmost respect and did not allow their relationship to be centered

on her disease. Even Carol, who did not specifically refer to one friendship also believed her friends not to think of her any differently because of her illness.

Irene, Ruth, and Carol indicated a lacking of excess disability in their friendships, as it seemed their friends treated them no differently for having Alzheimer's disease.

Diane's friendship was unlike the other respondents in that she would rely on her friend to help her in situations she would normally be fine performing in otherwise. Diane was thereby allowing a form of excess disability to be present in her friendship in allowing her friend to speak for her when she might have been able to herself.

Three of the four respondents indicated being affected by the stigma associated with having the disease. Irene was impacted by felt stigma in that her fears and shame prevented her from discussing her illness with friends, causing her to want to disengage. Diane was similar in that she knew all too well how Alzheimer's disease caused other to treat those with it differently, which prompted her to be more guarded with her diagnosis. Carol also discussed the stigma of the disease, and had the perception that others did not want to discuss it openly. Like Irene, she too was experiencing felt stigma.

Although Irene was extremely embarrassed of the effects of her disease, she had mentioned that her friends did not treat her differently because of it. Diane, however, had perceived that others had avoided her, whereby indicating a level of enacted stigma. She did not consider this to be the case with her good friend, but was under the impression that many others did not demonstrate her friend's level of understanding.

Irene and Diane both seemed to be affected by the stigma of the disease, in a similar way, in that it affected their levels of guardedness with their friends. These two,

however, were different in regards to their good friend. Although both of these women had experienced either felt or enacted stigma, Diane could be completely open with her friend, whereas Irene could not. Diane's friend's understanding of the illness caused Diane to be comfortable discussing it. It was not clear whether Irene's friend demonstrated the same level of understanding, but regardless, she was a known gossip, resulting in Irene guarding her words.

Fears and anxieties experienced on behalf of both the person with Alzheimer's and her cognitively intact friend pertaining to the friendship:

Both Irene and Diane in particular suspected their relationship with their good friend would remain despite the presence of their illness. Overall, the respondents did not display fears that their friendships would dissolve. The fears Irene, Ruth and Diane reported did not pertain to their friendships, but were related to their own state of being while out in public. Carol, however, did not have any fears related to her disease in any way.

Even though I could not adequately measure the friends' levels of fear, the respondents reported that their friends did not fear developing the disease. Although Ruth's good friend was no longer living, when she was alive, she continued close contact with Ruth. This indicates that had she been concerned about developing Alzheimer's, she did not display that within the friendship.

Communication challenges experienced by the person with Alzheimer's while interacting with her friend:

Irene, Ruth, and Diane all did experience difficulties in communicating with other people. Each of them was aware that when in a public setting, they might not say or do the right thing. As a result of these difficulties, Irene listened rather than spoke and Diane constantly guarded herself. Irene and Ruth did not explicitly express such challenges as being an issue in regards to their good friend, however. Where Irene and Diane's communication difficulties caused them to be guarded in conversations with others, Ruth had rather tell others the reason they were happening.

Unlike Irene and Ruth, Diane did explicitly mention sometimes having a hard time grasping the right words when speaking with her good friend. When this would happen, she would just simply allow her friend to try to explain what she had been trying to say.

Unlike the others, only Carol did not mention experiencing any communication challenges with her friends or in general. Again, because of the possibility of Carol's further progression of the disease compared to the others, she might not have perceived any challenges, but most likely did experience them.

The lack of companionship and open dialogue as experienced by the person with Alzheimer's surrounding her illness experience:

Ruth and Diane were both able to discuss their experience of the disease with their good friend and regularly did so. Ruth could no longer do that however,

considering her friend had died. Carol also had no problems in discussing her illness with her friends.

Although these three women found themselves able to share their experience of the disease with some of their friends, they (as well as Irene) had the commonality of not having the companionship of another who shared a similar experience. Since their friends did not have the disease, they could not completely understand what the women were going through. Particularly for Ruth and Diane although a friend was educated about the disease or kept abreast of the situation, it still did not prevent against the loneliness that invaded their lives.

Irene was unlike the other women in that she did not discuss her illness with her good friend; in fact, it had never been a topic of conversation for them. Irene was the only respondent who exhibited a completely closed dialogue surrounding her disease experience in the context of her friendship.

Role reformation to take place between the friends causing them to re-examine their expectations of each other:

Role reformation was not readily evident in at least two of the women's cases. Irene and Carol were similar in regards to role reformation in that neither had to redefine their expectations of the friendships in which they were involved. For Irene, this was on a dyadic level with her good friend, as they exchanged the same amount of support as in previous times, the same holding true for Carol on a network level. Neither of these women mentioned relying on their friends for anything as a result of the disease.

Ruth's friendship also did not display any role reformation, but this was for another reason. She had not met her good friend until after she had been diagnosed with Alzheimer's disease and therefore had no basis for comparison.

Diane was the only woman whose friendship displayed any change in roles during its course. Diane now found herself relying on her friend to provide her with words when she found it too difficult to find them herself. She was also aware that her friend was now keeping an eye on her in a protective way that she had not before.

The decrease of solidarity between the person with Alzheimer's and her friend:

Neither Irene nor Diane expressed that their level of closeness with their friend (or friends, in the case of Carol) had decreased at all. Both thought there to be no reason for their relationship with their good friend to get any weaker. Diane, for that matter, believed that her friendship had actually grown stronger since she had been diagnosed with Alzheimer's disease. This measure did not apply in Ruth's situation; her friendship was formed post-diagnosis and since then had ended due to death.

The gradual shrinkage of the friendship network of the person with Alzheimer's eventually resulting in her social isolation:

Ruth and Diane once had extensive friendship networks but since being diagnosed with Alzheimer's, both had fewer friends than in previous times. These two were becoming more isolated as a result despite their desire to remain socially engaged with friends.

Ruth and Carol were similar in that moves late in life had affected their friendship networks. Both of the women had contacted their friends from their former towns, but

the geographic distance was somewhat of a barrier to the full continuation of these friendships.

Irene had the same amount of friends as she had prior to her diagnosis although she clearly displayed the desire to socially withdraw. In that way, her situation regarding friends was the opposite of Ruth and Diane's since they wanted to stay engaged but were not.

Carol was unlike any of the other women in that her desire to stay engaged was actually fulfilled in her present social situation. Not only had she continued in her friendships of old, but she had also made new ones as a result of her involvement at the Senior Center. In this way, her friendship network had not decreased and she was not isolated.

A balance of realism versus optimism for the person with Alzheimer's and her cognitively intact friend:

Irene and Carol did not appear to show a balance of realism and optimism in their friendships. It was not clear whether Irene and her friend even encountered such a situation due to the lack of open dialogue surrounding her illness. Because she and her friend did not openly discuss the illness, it was not clear whether they were able to remain positive while also rising to the challenge of dealing with the disease. Although she was able to speak about the disease, Carol's friendships did not seem to be reflective of such a balance either. Carol did not show that her disease was an issue in her friendships and did not demonstrate that she and her friends ever grappled with the effects it may have had on those relationships.

Both Ruth and Diane's friendships maintained a balance between learning how to remain positive while rising to the challenge of dealing with the progressing illness. Ruth and her friend were able to talk about her disease and in that way be realistic about her situation. They also had no problems in having fun. Likewise, Diane could easily discuss the difficulties she was facing, but was not required to while around her friend. Both of these women's friendships were positive in nature but also allowed room for honesty about their experiences relating to the disease.

The cumulative effects of the negative thoughts, feelings, and behaviors exchanged within the friendship of the person with Alzheimer's and her cognitively intact friend to result in the dissolution of the friendship:

These women's friendships did not dissolve because of negative processes. Overall, Irene, Ruth, and Diane's relationships with their good friend simply did not have negative processes. Irene's friend's gossip problem was the only negative process within their friendship and was largely unrelated to her disease. This dyad's lack of negative processes might have been due to Irene's tendency to keep her friend at a distance (as evidenced by not discussing the illness with her), which could have meant the friendship had less chance for negative processes than one higher in solidarity.

The level of fun had in Ruth's friendship might not have permitted any room for negative processes in the relationship. If Ruth's friend had other friends, there might have been more of a chance for negative processes in that she might have been less satisfied in the friendship, and thereby might have treated Ruth differently. Likewise, Carol's friendships were not generally characterized by negative processes, however, her

perception of this could have been due to a possible lack of awareness surrounding the reality of her social situation. The lack of negative processes, however also might have been due to her having friends who were understanding. Diane's friendship lacked negative processes largely because her friend's sense of understanding of both her and the situation, which was likely due to her friend's general nature and occupation.

Not only did their friendships lack negative processes, but Irene and Diane had also retained their relationships with their good friend throughout the course of their disease. Likewise, on a network level, Carol's friendships had also remained. Ruth's friendship had also remained until her friend's death. Generally speaking, there were no differences between the women regarding negative processes within their friendships because none of them readily displayed any. Also, the only dissolution that happened in any of the respondent's good friendships was due to the death of one dyad member, whereby indicating that negative processes did not cause the friendship to end.

The formation of potentially enriching new friendships for the person with Alzheimer's post-diagnosis:

Ruth, Carol, and Diane had all been involved in new friendships since their diagnosis. Ruth's friendship in particular was of great significance for her, as she and her friend became quite close in a short amount of time. Carol as well enjoyed her friendships as she was able to interact with the same individuals every day through her involvement with the Senior Center. Likewise, Diane was able to relate to a whole new group of friends in her relationships with the women affiliated with the Alzheimer's

Association. These women understood what she was dealing with possibly even better than she did.

Irene was the only respondent that had not made any new friends since her diagnosis. She also, however did not have the desire to do so largely because of her fear while interacting with others.

Summary

Generally speaking, when I compared each participant's case to the set of informal hypotheses I generated during my review of the literature, I found that some of the women shared the same experiences while others simply did not. The reasons for such differences were not in a uniform manner among the cases. For instance, Diane had open dialogue with her friend, as did Ruth until her friend died. Diane's ability to discuss her disease with her friend was most likely due to the familial tie they shared as well as her friend's general sense of understanding. Ruth on the other hand would have shared about her disease with anyone, which was most likely the reason she was so inclined to be open about her illness with her good friend.

Likewise, Irene and Carol's friendships did not seem to have a balance of realism versus optimism, whereas Ruth and Diane's did. Unlike Carol's friendships, Irene's did not simply because she did not openly engage with her friends about her illness. It was unclear why Carol's friendships seemed to lack this balance. One possibility was that Carol might have lacked the awareness to engage in this balance with her friends.

I have reduced the possible explanations for the similarities and differences between the respondents' friendship patterns to three emergent themes. In the following

sections, I will discuss the factors that facilitated and constrained the women's friendships, their fulfilled and unfulfilled friendship aspirations and the evidence of continuity in relating to friends throughout their life-course.

Factors Acting to Facilitate or Constrain Friendships

It was evident throughout my analysis of the data that the differences and similarities between cases were at least in part due to certain factors that acted to either constrain or facilitate the participants' friendships. These factors were both intrinsic and extrinsic for the person with Alzheimer's in that some were beyond the respondents' control and others were not. If, for instance the participant did not have the personal desire to be involved in friendships, this would largely be an intrinsic factor that would likely act to constrain friendships from forming or continuing. The respondent's age could also act to constrain her friendships, but would be considered an extrinsic factor because it was not in her control. For the purpose of this analysis, I categorized each factor in the way that it appeared to fit best although there most certainly were factors that could be categorized differently depending on how one examined them (i.e., the shame of the respondent's illness might be seen either as an intrinsic or extrinsic factor acting to constrain her friendship). Ultimately, the convergence of these factors was influential in helping determine the participants' friendship patterns. Table 4 outlines each of these factors.

Table 4

Factors Acting to Facilitate or Constrain Friendships

<i>Extrinsic facilitators</i>	<i>Intrinsic facilitators</i>
Caregiver's influence Medical doctor's orders Organizational involvement (church, senior center) A friend's pursuit of the person Compatibility with a friend Friend's similar demographic characteristics	The desire for friendships Concern for his or her caregiver's experience No shame about his or her illness
<i>Extrinsic constraints</i>	<i>Intrinsic constraints</i>
Old age A friend's death Geographic relocation A friend's lack of pursuit The lack of a place for social engagement	The lacking of desire for friendships Fears of interacting Experience of shame
Note. Intrinsic factors are those inherently within the control of the person with Alzheimer's. Extrinsic factors are those originating from an external source and that can be considered largely outside of the person with Alzheimer's control.	

Extrinsic Factors Acting to Facilitate Friendships

The presence of a caregiver is a factor that can serve to facilitate the friendships of persons with Alzheimer's. Irene's husband and Ruth's daughter both saw the need for their involvement with friends and were instrumental in making this happen. Irene was continuing in her old friendships because her husband made sure they attended every social function they could. Likewise, Ruth had become good friends with another woman close to her age because of her daughter introducing the two.

A medical doctor's orders to stay socially engaged can also aid in the facilitation of friendships for the person with Alzheimer's. Irene's doctor had told her that she should continue just as she had been doing. Her husband saw his role as carrying out

these orders, and therefore kept her involved with her friends. During the interview, he adamantly expressed how good her friends had been to her and explained that things were as though they always had been. In this way, he was persistent about not letting Irene disengage, whereby fulfilling what the doctor had prescribed.

Organizational involvement for the person with Alzheimer's makes it easier to continue old friendships and to form new ones. Irene, Ruth, and Diane all mentioned their churches having facilitated friendships. Irene's primary network was a group of church women and her attendance at church functions translated to her continuation of those relationships. Likewise, Diane was able to continue certain friendships as a result of church involvement. Ruth had been attending church and had made a friend while there. She had stopped attending as regularly, however, and as a result was no longer meeting new potential friends. At least occasional church attendance for Ruth might have facilitated friendships. It is not always necessary, however, as Ruth's friend was still coming by, and making contact with her. As with church involvement, attendance at a Senior Center can also provide the person a place to interact with friends. Although she did not attend a church, Carol's involvement at the local Senior Center provided her friends with whom she could interact on a regular basis.

Another factor that influences the facilitation of the friendships of a person with Alzheimer's is her friend's pursuit of her. Irene's good friend initiated contact with her frequently, calling her far more than Irene did in return. Irene's friendship likely would have not continued in the way it had were it not for her friend's persistent contact. In a similar manner, Ruth's younger friend from church also pursued a friendship with her.

This woman had kind of adopted Ruth, taking her on family outings and had included Ruth as a part of her life. Had her friend not initiated much of the contact, Ruth likely would not have maintained the friendship. Diane's friends also regularly attempted to contact her and in that way were attempting to continue their friendships with her. She, however, often avoided contact with them. Although many of Diane's friendships were no longer close, had her friends not pursued her, the relationships would have most likely not continued at all.

A general sense of compatibility between the person with Alzheimer's and her friend is also helpful in the formation or continuation of the friendship. Irene and her friend had traveled extensively together with their husbands and had built years of shared memories. Their friendship was based on their enjoyment of the same kinds of activities while in a foursome with their husbands. Although Ruth's friend was no longer living, they had also once shared fun times together as "two silly old women." They were similar to each other, liked the same kinds of things and shared the ability to have a good time no matter what they were doing. Likewise, Carol was able to get along with her friends because they participated in the same sorts of activities together at the Senior Center. These were friends who were somewhat similar in age and who enjoyed talking and sharing with each other on a daily basis. Diane and her friend's difference in age did not matter as they were extremely compatible with each other, and able to get along quite well. The two shared the common bond of knowing how to deal with particularly difficult family circumstances, and had done that together in times past.

Lastly, similarity in demographic characteristics between dyad members can make it easier for the person with Alzheimer's to sustain old or form new friendships. None of these women explicitly mentioned this kind of commonality being a factor that facilitated their friendships. There was, however, a striking sense of homogeneity among the women and their friends as evidenced by Irene, Ruth, and Diane all identifying Christian women as their good friends (two characteristics which all three of the women also shared).

Intrinsic Factors Acting to Facilitate Friendships

As intuitive as it may be, the person with Alzheimer's simple desire to make new friendships or continue old ones can help determine whether or not she actually will. Ruth, Carol, and Diane all had the desire to continue to have friends. As a result, Ruth had made a new good friend with her daughter's help. Carol also was actively meeting and spending time with new friends at the Senior Center. Diane had met new friends through the Alzheimer's Association and would have liked to continue in her friendships from previous years. As I later explain, regardless of whether the person with Alzheimer's wants to make new friendships, she might find it challenging in the face of her disease.

In a similar fashion, the person with Alzheimer's concern for her caregiver's experience can also prompt her to continue in previously held friendships. Irene did not want to change her husband's life any more than it had and as a result continuing in her friendships enabled him to stay engaged with his friends as well. Her concern for him caused her to stay engaged with friends for his benefit and not her own.

The person with Alzheimer's might find it easier to be involved in friendships when she has no shame about her illness. Unlike Irene and Diane, both Ruth and Carol had no qualms or worries in discussing their illness with friends, which provided them a level of freedom in continuing old friendships and making new ones. The latter two respondents might have been more likely to have friends as a result of their general openness about what they were experiencing, unlike those who were more guarded about discussing it.

Extrinsic Factors Acting to Constrain Friendships

Not only are there factors that can help facilitate the friendships of persons with Alzheimer's but there are factors that help constrain such friendships as well. Old age can be a barrier to the formation and continuation of friendships. Ruth, for instance found it difficult to have friendships despite her desire to do so because she thought other older people did not get out much and in general were not fun to be around. Her age also meant that her younger friend was not as free as she was because of family duties that Ruth had already been through earlier in life. Ruth's friend who was both similar in age and liked to have fun had died. Some of the implications involved with being an older adult can make it difficult to form new friendships and continue old ones.

A move late in life for the person with Alzheimer's can also provide a barrier to friendships. Ruth had to leave the longstanding friendships of her former community behind when she moved to North Carolina with her daughter. The miles separating her from her friends resulted in her not having the same friends from previous years.

Likewise, Carol had moved, and although she did continue her former friendships, it was more expensive to call and keep in contact with those particular friends.

Intrinsic Factors Acting to Constrain Friendships

The person with Alzheimer's fears that she will say or do something inappropriate while out in public can also constrain her friendships. Both Irene and Diane knew they had difficulties while communicating, which resulted in them being afraid to interact with friends. Irene's fears resulted in her not wanting to make new friends and even wanting to disengage from previous friendships. Likewise, Diane was not as apt to form new friendships and did not engage in her old ones like she would have in previous times even though she had the desire to remain engaged with friends.

The experience of stigma for the person with Alzheimer's may also serve to constrain her from staying involved in friendships. Diane was withdrawing from her friends partly because of the shame of her disease. She felt ashamed of her disease and had possibly even experienced enacted stigma (an extrinsic factor) in that she perceived others to have avoided her at times. As a result, she could no longer identify a good friend who was not a family member, whereas this would not have been difficult in former times.

Summary

In conclusion, the participants in this study had factors that served to both facilitate and constrain them from making new friends and continuing to engage with old ones. Any one of these factors alone was not enough to determine the present reality of the respondents' friendship patterns. For instance, although Diane's friends were

pursuing her (an extrinsic factor acting to facilitate), her network had still decreased in size. Furthermore, the presence or absence of the same factor might have different outcomes for different respondents. Carol's geographic relocation (an extrinsic factor acting to constrain) had not impacted her network nearly as much as Ruth's, whose network size had considerably decreased. Put more simply, the factors that facilitated and constrained friendships came together for each of the respondents in a unique way, which in turn was influential in forming their friendship patterns.

Fulfilled versus Unfulfilled Friendship Aspirations

Another theme that emerged while I was analyzing the data is what I considered the inability versus the ability to fulfill one's aspirations in that what respondents would have preferred was different from the actuality of their present situation. Three of the four respondents displayed this concept. Irene's case illustrated this theme in that she simply wanted to remain at home; a place where she did not have to be around friends. Her desire was not fulfilled, however, because she was still actively engaged with her network of friends for her husband's benefit. Ruth and Diane represented the opposite situation in that they wanted to remain engaged with friends, but were not doing so. Ruth's lack of an opportunity to meet people combined with the move from her previous town resulted in a much smaller network than she would have liked. Diane, likewise, wanted to continue in her old friendships but was largely not doing so because of her fears while around others. Carol's situation was the only one that did not reflect the inability to fulfill her aspirations. Her desire to make new friends was fulfilled through her involvement at the Senior Center.

Although most of the respondents would have preferred different patterns than the ones they currently had, they did have at least a measure of control over their friendship situations. Irene could have, for instance, remained at home while her husband went out with their friends. Ruth also could have continued attending church, which would have guaranteed interaction with potential friends. Likewise, Diane could have reciprocated when her friends pursued her. In this way, these women did not always engage in behaviors that would have resulted in their preferred friendship patterns; they were, however, at least somewhat aware that what they would have preferred did not match their current situation.

Continuity Within the Women's Lives

Although other researchers (i.e., Clare, 2003; Goldsmith, 1996; Phinney, 1998) have documented a sense of continuity for persons with Alzheimer's, I still consider this an emergent theme in the current study. Continuity was evident in all four of the women's cases but was manifest in different ways. Irene and Carol's continuity was external in nature because their current friendship patterns were largely similar to their previous ones (Atchley, 1989). I distinguish their sense of continuity from Ruth and Diane's because it was overt and could be seen by others. Essentially, their current patterns were clearly indicative of their pasts because they had formerly been active in their friendship networks and were continuing in this way. Irene remained involved in her friendships, but chose to keep them at a distance, whereby still relating to others in a guarded way. Carol also continued her friendships and related to friends as openly as before, discussing Alzheimer's disease with any of them. Both of these women were

engaged in external continuity in that it was clearly evident that their friendship patterns remained similar throughout the course of the disease.

Unlike Irene and Carol, Ruth's situation was more illustrative of internal rather than external continuity (Atchley, 1989). Although her friendship network had changed and was now characterized by a general loss of friends and in that way looked different from previous years, her personality had persisted throughout her disease. Inherently, Ruth was still the same in that she tended to have things out in the open and was willing to talk to anybody. Although she did not have anyone still alive that she could identify as a good friend, if she had, that person would have most certainly known about her disease. As was the case before her diagnosis, when she was in public, she would be willing to speak with anyone.

Unlike Ruth, Diane had experienced a change in personality, causing her to acknowledge she was no longer was the person she once had been. Whereas she once had been an extrovert who would participate in anything, she now routinely cancelled social engagements due to her fear of interacting with others. The changes in her patterns of behavior and ways of relating to others had resulted in her having a smaller friendship network than had in times past with very few friends she was actually comfortable being around. Although it is impossible in the present study to assert that the disease was the primary force acting to change her friendship patterns, it is at least somewhat evident that it was somehow related to this change.

Although Diane's situation could be illustrative of a discontinuity of experience, I assert that she actually was displaying a level of internal continuity, in that her

understanding of her present friendship situation was largely tied to her memories of her past and how she once had been (Atchley, 1989). Although she was a “different person” she still was able to tie her past behaviors to her present experience in order to adapt to the Alzheimer’s related changes. She no longer had the same friendship network, or personality for that matter even, but was at least was aware of what her life had previously been like.

Conclusions

Each woman’s story provided a different account of the experience of Alzheimer’s disease and more specifically how it related to a good friendship. Likewise, each woman displayed varying friendship patterns, the possible explanations for which included various factors that acted to facilitate and constrain friendships, fulfilled versus unfulfilled friendship aspirations, as well as a sense of continuity reflected in at least some form for each of the women.

CHAPTER VII

SUBSTANTIVE DISCUSSION

Expected versus Actual Findings

As the previous two chapters have outlined, there was a set of informal hypotheses I gathered from my review of the literature and used to frame my questioning of the respondents in order to know how to analyze the data I collected. Although Chapter six provided the similarities and differences of the respondents regarding each of these informal hypotheses, the present chapter also addresses them in order to summarize these findings and reconcile them with the existing literature. A discussion of the unexpected finding of a general lack of negative friendship processes as well as the sense of continuity in each of the women's lives follows. Toward the end of this chapter, I also show how the life-course perspective helps explain the respondent's friendship patterns. Although the women I interviewed during this study are not representative of other women with Alzheimer's disease, their experiences do provide at least some understanding of mixed friendships as the following sections illustrate.

What are the Patterns that Characterize Mixed Friendships?

Social Support

The participants in this study indicated that although they may have exchanged relatively equal amounts of support with their friends, it was important for them to know that they could rely on their friends (Wenger's study on the general older adult population

did as well, 1990). The respondents gave further support to the previous finding that marriages often guarantee spousal support for the person with Alzheimer's (Wenger, 1994) in that married respondents relied on their husbands more than their friends. Contrary to other findings (Ficker et al., 2002) the respondents did not hold the perception of receiving lowered amounts of social support.

Awareness of Differences with Friend

Even though homophily generally characterizes older adults' friendships (Blieszner & Adams, 1992; Gutheil, 1991), not all respondents showed evidence of its lack to be a problem in their friendships. For some, being aware of the difference in cognitive functioning had little effect, which permitted them to continue in friendships as before. For others, however, the lack of homophily caused them to prefer to be alone and to avoid contact with friends.

Negative Processes Leading to Negative Outcomes

Although negative processes might have characterized friendships that the participants did not report on, they did not characterize the participants' good friendships (contrary to other studies, i.e., Sabat, 1994; 2002). For instance, even when a friendship had an element of excess disability, it did not necessarily result in a loss of autonomy for the person with Alzheimer's (also contrary to previous research, Chiriboga, 2001). There were situations when a friend's help that was not absolutely needed actually resulted in comfort for the person with Alzheimer's.

Likewise, even when stigma was present, it did not always result in a negative outcome for the person with Alzheimer's. Conversely, stigma did result in some

respondents wanting to avoid friends and most likely affected whether they chose to disclose the diagnosis to friends (also found by Snyder, 2002). As reported with other stigmatized populations (Green, Davis, Karshmer, Marsh, & Straight, 2005), the participants' disability did sometimes create a social awkwardness that interfered with their ability to have ordinary social interactions.

Fears and Anxieties within the Friendship

The participants of this study also demonstrated that mixed friendships are not necessarily characterized by fears and anxieties. Contrary to other research (Gwyther, 1997) not all respondents were worried about the potential dissolution of their friendship. The respondents' friends provided the assurance of unconditional acceptance. This finding illustrated that acceptance from a good friend is important in mixed friendships and may be connected to the person with Alzheimer's lack of fear of the friendship dissolving. For some, their primary fear was largely unrelated to their friendships and instead regarded making "mistakes" while in public settings (previously reported by Gillies, 2000).

Communication Challenges

Supporting the notion that communication challenges can affect friendship sustainment (Ficker et al., 2002), the participants of this study were sometimes less comfortable speaking with friends (also found by Clare, 2002 and Phinney, 1998) and more guarded, thereby preventing friends from getting closer. Communication challenges also prevented some respondents from forming new friendships because of their tendency to avoid contact with other people (previously reported by Gillies, 2000).

and Phinney, 1998). These difficulties did not necessarily result in the same outcomes for all participants, however. In some cases, they prompted the person with Alzheimer's to readily disclose her diagnosis and did not inhibit her from interacting with friends. Participants' friendships also demonstrated that cognitively intact friends can aid with communication challenges, doing whatever is necessary to help the person with Alzheimer's articulate her thoughts.

Companionship and Open Dialogue

The present study indicated that persons with Alzheimer's may or may not be guarded with cognitively intact friends about their illness. This was dependent on a variety of things for the respondents of this study, such as their personalities and social histories, their trust of the person with whom they were friends and their overall experience of stigma. The friend's general knowledge of the disease also affected whether the person with Alzheimer's decided to disclose her diagnosis. Contrary to the respondents of another study (Clare, 2002), not all participants lacked the opportunity to discuss their illness, however, some of them did show evidence of a lack of companionship with others who could understand their experience.

It was sometimes the case the more knowledgeable the friend, the more comfortable the participant was in discussing her disease. The women in this study also demonstrated that although the person with Alzheimer's might have been guarded about her illness, not having told anyone, friends might still know about it. As shown in another study (Van Dijkhuizen et al., 2006) closed communication does characterize

some friendships in that Alzheimer's disease is not always a topic of conversation, regardless of the friendship's duration.

Role Reformation

Although persons with Alzheimer's routinely need help from friends (Phinney, 1998), the friendships in this study were not always characterized by role reformation. At least one friendship had become different, however, in that the respondent's friend now supported her by helping others understand what she was experiencing. Likewise, the participants' friends demonstrated that those who are cognitively intact may begin to keep a watchful eye on the person with Alzheimer's.

Solidarity

The participants of this study demonstrated that lowered levels of solidarity do not always characterize mixed friendships, which runs contrary to another finding (Ficker et al., 2002). The respondents' illness was at times associated with a heightening of solidarity in that it may have helped bond them closer together with their friends. Lastly, these friendships showed the possibility of future growth when the person with Alzheimer's believed the friend to be dependable in the future.

Network Size

As reported elsewhere (i.e., Clare, 2002; Corner & Bond, 2004; Phinney, 1998; Snyder, 2002; Wenger, 1990) this study demonstrated that the friendship networks of persons with Alzheimer's do sometimes shrink which happens for differing reasons (also described by Adams, 1987). A move late in life, a friend's death, or the person with Alzheimer's fear while interacting with others were all reasons for a lower number of

friends for participants. This finding supports previous accounts of network changes that are outside of a person's control (Jerome & Wenger, 1999). On the other hand, respondents also demonstrated that friendship networks sometimes remain the same size. Organizational involvement as well as concern for their spouse's experience helped some participants retain their friendship network. The participants of Pearce and her colleagues' (2002) study also demonstrated the concern for their caregiver's experience. Unlike those whom Corner & Bond (2004) surveyed, these respondents did not show evidence of having sought out old friends who avoided them.

Realism versus Optimism

The friendships examined in this study showed evidence of a balance of realism versus optimism, in that dyad members could realistically discuss the disease but were not compelled to allow it to be the theme of their friendship. As with both Clare's (2002) and Yale's (1999) participants, these women's friendships might have been sustained due in part to this balance. Respondents also engaged in this balance on an individual level as well. They reported doing the best they could with their situation (as with Pearce and her colleagues' study, 2002) and were sometimes even thankful for their past without the disease (as previously reported by Kitwood, 1997).

Negative Processes and the Dissolution of Friendships

Contrary to other research (i.e., Aarsten et al., 2004), this study found that not all mixed friendships dissolve. Furthermore, respondents showed that friendship dissolution might be unrelated to negative processes, due instead to other factors, such as death (Wenger reported death as the most common reason for the dissolution of older adults'

friendships, 1990). A move late in life caused one respondent's friendship network to dissolve, supporting the notion that maintaining friends over distance requires more effort than with ones who are local (Wenger, 1990). Because the friendships reported on in this study were sustained throughout the course of the participants' illness, they clearly downplayed the existence of negative processes and showed that not all cognitively intact friends distance themselves (contrary to Goldsmith's research, 1996). There, however, may have been other friendships the participants did not report on in which negative processes led to friendship dissolution.

New Friendships for the Person with Alzheimer's

Although not all respondents had the desire to form new friendships (as also reported in the general older adult population by Jerrome & Wenger, 1999), there was the likelihood of forming new friendships post-diagnosis, supporting previous research by Williams & Roberts (1995). In order for the person with Alzheimer's to make new friendships after her diagnosis, she needed both the desire and the opportunity to be there, along with the courage to do it. Although at least one participant became friends with a younger person after her diagnosis, she did not categorize that particular friendship in the same regard as one involving an individual of a similar age (also reported by Wenger, 1990, in the general older adult population). Furthermore, these respondents showed that having the disease could actually facilitate friendships that would have otherwise not been formed. As in the case of one woman, involvement with the Alzheimer's Association offered a source of friends who were knowledgeable about the disease.

General Lack of Negative Processes

Alzheimer's disease did not necessarily have a negative impact on the mixed friendships under study in the present research. Many of the negative processes I believed would characterize the relationships between the participants and their good friends simply were not there or I did not detect them. There were instances of stigma, but it was not necessarily on a dyadic level between the person with Alzheimer's and her good friend. Although one respondent's decision not to discuss her diagnosis with her friend might have been connected to the stigma she experienced, it was also probably due to her friend's tendency to gossip. Another respondent was concerned about with whom she discussed her disease and on the whole had become disengaged from her friends due to her fears of interacting with others. For this reason, this particular respondent's friendship patterns seemed to have changed the most in connection with her disease from the stigma with which it was associated.

Although both of these respondents were affected by stigma on a network level, the other two seemed relatively unaffected by it. For instance, one woman was aware of the stigma associated with her disease, but she did not let it affect the way she related to her friends. She in fact would rather have discussed it with them because they most likely had not had an opportunity to talk about it before.

Washburn & Sands' (2006) study indicates that persons with dementia can maintain personal relationships. Contrary to what I expected, the participants of this study supported this finding by showing in particular that persons with Alzheimer's can engage in friendships. Furthermore, friendships might take on a new form with

Alzheimer's disease in a positive way. Although the friends might have been close before the diagnosis, the person with Alzheimer's and his or her friend might become even closer afterwards. Essentially, when a friend offers the person with Alzheimer's comfort (a need which is heightened by the sheer presence of the illness), that friend enables the person to remain in one piece when she or he is in danger of falling apart (Kitwood, 1997).

Another unexpected finding was that the person with Alzheimer's network did not always breakdown, and if it did, it was not necessarily for the reason I had expected. One respondent's network had broken down most likely because of her move. The decrease in friends was, however still plausibly connected to her disease in that the reason for her move was due to her cognitive decline.

Continuity Theory & the Life-Course Perspective

Another finding contrary to my initial expectations was the presence of continuity within each of the participants' experiences. Continuity theory (Atchley, 1989) posits the changes an older adult experiences are adaptive in that they allow the individual to frame his or her present situation in terms of his or her past. Essentially, the evolution of the person's life becomes a cohesive story, where the past is reflective of the present, which in turn is reflective of the future. Irene and Carol demonstrated external continuity in that they continued in their friendships from previous times and related to friends in the same ways as before. Ruth and Diane's situations offered examples of internal continuity, in that although they no longer had as many friends as before, they still retained a

knowledge of their past friendship patterns. They used this awareness of the past to better deal with their present situation.

Continuity theory also posits that people with fairly recent impairments must cope with pressures from others to maintain external continuity. Irene was clearly affected by such pressures in that her husband was adamant about her continuing in her friendships like in previous times despite her desire to do otherwise. I concur with Atchley's (1989) assertion that even though the individual might need to change, she or he might not be allowed by those who pressure the continuation of past behaviors.

Irene, Ruth, and Carol's situations all support the notion that persons with Alzheimer's bring their personalities and social histories into the disease (Clare, 2003; Goldsmith, 1996; Kitwood, 1997; Sabat & Harré, 1992). Although Diane's personality had changed since her diagnosis, it was clear that she was aware of the changes she was experiencing and was adapting to her current situation. In the same way, the participants in Pearce and her colleagues' study (2002) demonstrated the evolution from the past to the present by balancing the knowledge of their former ways of relating to others to the difference of their present situation. In that way, Diane's case perhaps best illustrates the idea of a general adaptation to Alzheimer's disease regarding one's friendship patterns framed by the knowledge of one's past.

Essentially, each woman did experience a level of continuity, albeit reflected in different ways. Despite the similarities in each woman's experience of the disease, it was still largely an individual phenomenon resulting in different friendship patterns for each. As Kitwood (1997) declared, there are great differences for each person with Alzheimer's

disease. This declaration implies that researchers consider such differences and not expect a uniformity of experience for their friendship patterns.

The life-course perspective fits nicely with continuity theory in the present study to help explain the respondents' current friendship patterns. This perspective (Riley, 1979) posits that the aging experience is a lifelong process, any stage of which cannot be isolated without accounting for the individual's past. More simply, no one part of an individual's life can be understood apart from the others. The respondents of the present study demonstrated that their former ways of relating to others largely shaped their current friendship situations.

This perspective also illustrates how one's historical period impacts the aging process. The respondents of this study occupied a time period in which spending time with friends was a valued tradition. As a result, each were able to place value on friendships in a way they might not have had they belonged to a different historical period. In sum, these respondent's cases demonstrated that having Alzheimer's disease and the resulting impact on their friendships could not be understood without an adequate examination of their past behaviors, expectations for the future, and the historical period of which they occupied.

Summary

In sum, the findings of the present study demonstrated that the respondents' relationship with a good friend did not have to be characterized by negative processes. These participants sometimes were, however, affected by the disease's stigma, which might have determined how and if they continued in their friendship relations. Taken

together, continuity theory (Atchley, 1989) as well as the life-course perspective (Riley, 1979) helped explain the respondents' friendship experiences throughout the disease process. Lastly, although I could not generalize the findings of the present study to the entire population of persons with Alzheimer's, I was able to use them to generate hypotheses and possibilities for future studies, which I discuss in the following chapter.

CHAPTER VIII

OVERALL DISCUSSION OF METHODOLOGICAL AND SUBSTANTIVE THESES

Purpose of Study and Suggestions for Other Researchers

The initial purpose of the present study was to examine the friendship patterns of persons with Alzheimer's and cognitively intact individuals. Although existing research on the topic is scarce, it is feasible to conduct such studies. I documented each step prior to and during the data collection process in the current study and wrote about my findings for the substantive part of the study. What resulted were essentially two projects, one being related to the initial study topic (mixed friendship patterns) and the other related to how to survey the population (obtaining the firsthand accounts of persons with Alzheimer's). I intended for the convergence of both projects' results to be of use for others who are interested in studying the patterns of mixed friendships as described by the person with Alzheimer's.

As in the case of research on any topic with any population, there are certain things that the researcher can control and there are others that she or he cannot. Such things as questionnaire design and the general topics pursued within the interview are within the researchers' control. Scholars who want to engage in the inquiry of this topic by accessing this population need to be prepared to encounter factors and situations that are simply not within their realm of control as well. From the effect the IRB has on the design of the study, to the guarded nature of accessing the population, to the actual day of

the interview with the person with Alzheimer's, all of these are situations where the researcher might find his or her anticipated research design at someone else's mercy.

Situations within the Researcher's Control

Although this field of research most certainly needs firsthand accounts of persons with Alzheimer's on the topic of mixed friendships, it would be preferable to have their cognitively intact friends' perspectives as well. Essentially, I could have also recruited the person with Alzheimer's friend for participation in the study (except for in the case where the participant's friend had died, of course) in order to receive a fuller picture of the patterns occurring within the friendship. Having multiple perspectives would have strengthened the quality of the data. For instance, while attempting to measure the person-turned-patient mentality, I had asked each respondent if she thought her friend perceived her differently on account of her disease. I could not, however, adequately measure this concept by asking only the participant. I had no way of understanding what her friend actually thought of her, and whereby did not know whether her friend had allowed the participant's diagnosis to overshadow her status as a person.

Likewise, although I had asked respondents whether their friend ever reflected any fears of developing the illness as a result of contact with her (essentially, measuring whether the friend was facing her own mortality), I was unable to judge whether the friend actually thought about this. Even if the friend was afraid of developing Alzheimer's, she might have never spoken about it in the context of their friendship in an effort to remain sensitive to the person with Alzheimer's. Essentially, the data would have been more complete had I pursued the accounts of the participant's friend.

Researchers who study mixed friendships should take this into account and consider including the person with Alzheimer's friend in the population of study.

As with including different perspectives in the population of study, researchers also have the control to determine the questions they pose while engaged in the interview process. The design of such questions is imperative to the quality of the study.

Researchers should ask questions that elicit as comprehensive a picture as possible of the respondents' social histories and personalities. This is necessary in order to have a framework for which to analyze the participants' current friendship patterns. Quite simply, the person with Alzheimer's social history and personality carries into the illness (Goldsmith, 1996; Sabat, 1994) and much of the time can help explain his or her current way of relating to friends. Irene's case illustrated this continuity in that she had always kept things private from her good friend, partly due to her own personality and partly due to her friend's history as a known gossip. She was the only participant who had not disclosed her diagnosis to her good friend. By asking questions about Irene's background, I was able to better understand why she did not discuss her disease with her good friend or any of her other friends for that matter.

Even when the individual's personality post-diagnosis is not reflective of his or her past, researchers should still be aware of the traits that previously characterized the person with Alzheimer's. This was beneficial in Diane's case, for instance. Had she not disclosed that she formerly was one to be surrounded by many friends, actively engaged and extremely extroverted, I would not have considered her current behavior to be atypical. In essence, without an understanding of who she had been, I would not have

been alerted to a change in her friendship patterns when she indicated a tendency to disengage. Asking each respondent questions on how she formerly valued and related to friends enabled me to better understand if Alzheimer's disease might have been related to her current friendship patterns. Essentially, researchers who access this population in order to study this topic should design questions that are as comprehensive of the person with Alzheimer's former situation as possible in order to understand the meaning behind the respondent's current friendship patterns. It is worth mentioning, however, that regardless of what information a researcher gleans about a participant's past, it is still only a retrospective account that will largely be filtered through the disease experience. More simply, although quite valuable, retrospective accounts must not be weighted too heavily by the researcher.

Like the perspectives researchers obtain and the questions they design, the way they obtain informed consent is something within their control that will have a bearing on the nature of the study (although an IRB does have a measure of control in determining this). Researchers who choose to use capacity assessments to obtain consent need to be aware that they will likely only be sampling early-stage individuals. Although there is a clear bias in the research literature towards obtaining these perspectives (Downs, 1997), this was the population of intent in the present study. Had I designed the consent process in a different way, for instance, by pursuing proxy consent, I would have been able to sample later-stage individuals. In doing this, I might have found more evidence of negative friendship processes and network breakdowns related to the progression of the disease. Contrary to what one might think, a study sampling later-stage individuals

would provide valid and reliable data and could help explain mixed friendship patterns. Another study (Cowdell, 2008) has demonstrated that sampling later-stage individuals is completely feasible and that a caregiver's perspective is not a necessity in order to corroborate the data.

Situations outside of the Researcher's Control

As with the scientific inquiry of any topic on any population, there are certain items in the research process that are within the investigator's realm of control. Despite an IRB's influence, the researcher still largely functions autonomously to determine the range of perspectives she or he pursues, the design of study questions and the consent process. The researcher must be prepared, however, to address factors and situations that are simply outside of his or her control while conducting this kind of research. Those who endeavor to study mixed friendship patterns as described by the person with Alzheimer's should be forewarned that they are not the only determining presence in the course of their research.

Researchers studying this population must be prepared to encounter ethics-related situations that will inevitably have a bearing on their studies. The awareness of how to navigate an IRB while accessing this population is imperative for researchers because its presence will ultimately shape the data collection process and if it even happens at all. In the present study, the IRB mandated a loved one be present if the person with Alzheimer's so desired. As I explain later, this was beneficial in some instances, but not necessarily in others. If I had not been agreeable to this requirement, the IRB would not have allowed me to collect the data. In this way, the IRB not only shaped the study's

design (by adding a third party to the interview) but also shaped the data I collected (the presence of the third party elicited answers from respondents that might not have been given otherwise).

Another factor beyond the realm of a researcher's control involves the varied individuals with whom she or he will negotiate in order to access the population. As with the IRB, these individuals will affect if the researcher even collects the data and can determine what the data actually are. In all of the cases, the respondent's caregivers were instrumental in facilitating the interviews. The caregivers' presence or lack thereof during the interview also had an impact on the data I collected. Irene's husband, for instance, was quite vocal throughout the interview, often interrupting her to interject his own comments. He steadily convinced her of how good her friends were to her, which most likely had an effect on her responses. Essentially, had he not been there, the data might have been completely different.

Ruth's daughter also affected the data, but in this case helped her to identify her good friend and when asked, reminded Ruth of her death. Had she not been there, I would essentially have had an incomplete picture of Ruth's friendship patterns and would likely not have found that new enriching friendships are possible after a diagnosis of Alzheimer's disease. Unlike the other three interviews, Carol did not have a caregiver present. As a result, I was not certain that the friendship patterns she spoke about accurately represented her situation, and was under the impression they did not. Without the presence of a knowledgeable third party, I could not be certain. Ultimately, the

caregiver's influence and presence throughout the study can be either beneficial or detrimental and is largely outside of the researcher's control.

Although researchers do have agency in determining what questions they will ask and what techniques they will use in interviewing the population, this does not mean they will be entirely prepared for the actual interview. Quite simply, researchers cannot control the types of answers they receive to the questions they pose (nor should they want to). For instance, when I clearly asked Carol to identify one good friend, I was not prepared for her to speak on a network level the entire duration of the interview. I knew the nature of her answers was most likely related to the pathology of her disease. As a result, however, I could not compare her friendship patterns to the other cases in a uniform manner. Thankfully, the use of qualitative methods provided me with the flexibility to still incorporate her responses into the analysis.

In the same way, the other women who did actually identify a good friend responded in ways that I was not necessarily expecting. Although I attempted to narrow whom the respondent might identify, each woman broadened the definition in her own way. Ruth's good friend was no longer living (she had forgotten that, however). Diane's good friend was a family member (her disengagement since her diagnosis translated into very few good friends). Ultimately, although I asked for it, I was unable to require all of the respondents to identify a good friend according to my definition's constraints. I had not intended for respondents to speak about someone who had died or someone who was also a family member.

Another interview situation for which the researcher should be prepared is if it is difficult for respondents to reference their friendship patterns both before and after their diagnosis. For instance, it was not always clear whether Irene was referring to the time prior to her diagnosis or after it. Her friend had a tendency to call and check up on her, but it was not clear if this was only after she was diagnosed, or if this had always been the case. In Ruth's case, a "before" and "after" analysis of her friendship held no meaning. She had met her good friend after she was diagnosed with Alzheimer's which meant there was no basis for comparison of how her friend treated her prior to her diagnosis.

Along the same lines, the researcher must be prepared for the data not to fit into the predetermined codes she or he constructed prior to collecting the data. As with qualitative research on any topic, the researcher would be foolish to believe that she or he was aware of all of the possible codes and their variations in advance. For instance, in Diane's case, the concept of excess disability was not immediately clear; according to her, her friend treated her no different for having her disease. After mentioning that she relied on her friend in situations when she did not necessarily need it, I modified the concept to indicate that it could actually be a voluntary process on behalf of the person with Alzheimer's and not an entirely negative one either.

In summation, researchers of mixed friendship patterns who choose to survey persons with Alzheimer's must be prepared to address factors and situations that are simply outside of their control. The presence of an Institutional Review Board will have an impact on the study design. Likewise, the influence of a caregiver, whether by scheduling or being present during the interview will likely determine both the access to

and the actual substance of the data. Other factors that researchers will likely have no control over include receiving answers that do not necessarily make for easy comparisons between cases, as well as knowing how to analyze data that might or might not accurately represent the situation of the person with Alzheimer's. This latter situation raises the methodological question: to what extent can investigators meaningfully analyze data that might not be valid (Phinney, 1998)? In conclusion, researchers need to do what they can to ensure the quality of the data, however must recognize that they are not completely autonomous agents during the research process.

Directions for Future Inquiry on the Topic

Researchers who study this topic should give credence to the evidence provided in the current study that there are factors that both facilitate and constrain mixed friendships resulting in either fulfilled or unfulfilled friendship aspirations for the person with Alzheimer's. In studying factors that are beyond the control of the person with Alzheimer's, researchers can then focus on how to enable the fulfillment of the desires for those wanting to remain engaged with friends as well as for those not sharing this desire. A possible sub-stream of research likely resulting would deal with how the fulfillment of the person's friendship aspirations might increase his or her quality of life.

Although the outcome might seemingly be intuitive, another possible research direction would be to test whether studies using capacity assessments sampled primarily early-stage individuals. If the researcher were to identify that the use of a capacity assessment in obtaining informed consent did result in only sampling early-stage individuals, she or he might then search for ways to obtain consent from individuals in

the later stages of the disease. Studies focused on this topic would undoubtedly strengthen the methodological domain of this field of research.

Likewise, a researcher could also test whether the presence of another individual (i.e., a spouse or caregiver) during interviews had an effect on the answers of the person with Alzheimer's. In doing this, the researcher might show how data can vary depending on the privacy (or lack thereof) of such interviews. The simplest way to conduct such a study would be to interview the person with Alzheimer's at different times, once with and once without a caregiver present. The researcher would need to ask the respondent the same types of questions during each interview and then compare whether his or her responses differed between interviews in any way.

Furthermore, scholars need to conduct longitudinal studies in order to provide an understanding of how mixed friendships might change throughout the progression of the disease. Those who choose to design such studies should consider using continuity theory or a life-course perspective to help explain their findings. The strength of conducting a longitudinal study while employing these frameworks lies in the researcher's ability to chart firsthand the changes in friendship occurring over the individual's life and throughout his or her illness. Although this study did report on respondents' previous friendship patterns in order to understand their current ones, the retrospective nature of these accounts meant that they were not completely substantiated. Although continuity theory and the life-course perspective were useful in the present study to explain the respondents' friendship patterns, evidence of both of the frameworks would likely be more convincing while employed in the context of a longitudinal study.

Although science has not afforded scholars the ability to know whether one will or will not develop the disease, there are still ways of substantiating pre-diagnosis friendship patterns. For instance, a researcher could recruit individuals just beginning to experience cognitive difficulties without a specified diagnosis of Alzheimer's. Researchers choosing to sample these individuals would likely have participants who did not go on to develop the disease; however, for participants who did, the diagnosis could be one point along the trajectory for which to study the individuals' friendships. For these studies (and any other longitudinal ones) scholars would have the ability to chart whether mixed friendships are more likely to display negative processes over time, or whether persons with Alzheimer's networks are more likely to break down as the disease progresses.

Lastly, the connection between friendships and health for older adults (Jerome, 1990; Lennartsson, 1999) should provide further motivation to study the topic of friendships of persons with Alzheimer's. It is plausible for following investigations to examine whether the person with Alzheimer's involvement in friendships lessens the impact of the disease. As at least one study has suggested (Seidler, Bernhardt, Nienhaus & Frölich, 2003) one's involvement in social relationships can provide a protection against developing dementia. Although certainly a scientific leap, a direction for future research is to explicate whether friendships in particular can help prevent against Alzheimer's disease.

CHAPTER IX

OVERALL CONCLUSIONS OF METHODOLOGICAL AND SUBSTANTIVE THESES

The intent of the present study was to examine the friendship patterns of persons with Alzheimer's disease and cognitively intact individuals. At the outset of the research, I expected to find a host of negative patterns to characterize these friendships and expected a gradual decrease in the size of the person with Alzheimer's friendship network. After encountering unexpected circumstances while surveying the population in an attempt to answer the research question, I realized why there was such a paucity of inquiry on the topic in the existing literature. Recruiting participants can prove an arduous task.

The diagnostic procedure is not as clearly evident as one might think, meaning many persons in the early-stages of the disease who would be candidates for inclusion simply do not have the necessary diagnosis. Diagnostic centers are not always the best sources for recruitment as many clients have not necessarily accepted the diagnosis, nor are settings such as adult day centers, which serve individuals normally in the later-stages of the illness. The Alzheimer's Association provided three of the four women I interviewed and in that way proved the most lucrative agency for recruitment purposes.

Researchers attempting to survey persons with Alzheimer's in order to examine mixed friendship patterns must also be prepared to engage in a dance with IRBs,

professionals in the field of aging, as well as family caregivers in order to gain access to the person with Alzheimer's. The dance does not end here, however, as researchers must also carefully position their steps during the interview process, being willing to engage in any conversational method necessary to elicit the respondent's perspective, while being prepared for answers that will not fit neatly into their predetermined categories and codes. Investigators must expect the unexpected while surveying this population. Diane's suggestion to friends of persons with Alzheimer's can just as easily apply to researchers of the population, and that is quite simply, "React and go with it."

Although the findings of the present study cannot be generalized to all persons with Alzheimer's, it was evident for the respondents in this study that their mixed friendships demonstrated a variety of patterns in that some of the women remained engaged with friends and some did not. As these women illustrated, there are various reasons for why the person with Alzheimer's either does or does not remain engaged with friends, such as the presence of a caregiver, his or her opportunity or lack thereof to engage with friends, as well as his or her fears of embarrassment while interacting with friends. As Sabat (1994) suggested, the experience of every person with Alzheimer's varies because of the each person's own history, disease process, quality of relationships with others, and pre-diagnosis patterns of behavior. In the present study, the interaction of these factors was a unique process which acted to result in different friendship patterns for each respondent.

Furthermore, the friendships of persons with Alzheimer's and cognitively intact individuals are not necessarily characterized by negative processes. Often, these

friendships can be a source of acceptance, companionship and enjoyment for the person with Alzheimer's. Quite simply, a diagnosis of Alzheimer's disease does not have to signal the end of life (Jolley & Benbow, 2000) nor the end of rewarding friendships for those who have it.

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APPENDIX A: INTERVIEWING DOCUMENTS

Consent Form
UNIVERSITY OF NORTH CAROLINA AT GREENSBORO
CONSENT TO ACT AS A HUMAN PARTICIPANT: LONG FORM

Project Title: Mixed friendships: Examining the friendship patterns between persons with dementia and/or Alzheimer's disease and cognitively intact individuals

Project Director: Brandi M. McCullough

Participant's Name:

DESCRIPTION AND EXPLANATION OF PROCEDURES:

Brandi McCullough, a student of the UNCG Sociology Department, is conducting a study on the friendships of individuals who have developed dementia and/or Alzheimer's disease. You were selected for participation in this study because of your diagnosis of dementia and/or Alzheimer's disease.

You will be participating in a face-to-face, private interview that will last between one and two hours. You will be asked a general set of questions about your experience of dementia and/or Alzheimer's disease and about what your friendships were like before you were diagnosed and what they are like at the present time.

You may ask questions at any time throughout the interview.

Your interview will be audio-taped. All of the information provided during your interview will be transferred to the researcher's personal computer, which is protected by a password. The recording for this interview will be deleted after the interview has been transcribed, and the transcriptions from this interview will be destroyed after they have been analyzed.

RISKS AND DISCOMFORTS:

There is a small possibility that you may experience feelings of discomfort as a result of the interview questions. Should this occur, the researcher will offer to help you contact someone of your choosing to assist you with handling these feelings.

POTENTIAL BENEFITS:

This interview might benefit you by allowing you the opportunity to be able to openly discuss your experience of Alzheimer's disease. You will be provided with an executive summary of the study upon its completion. This study will add to what researchers already know about what it is like to be a person with Alzheimer's disease.

CONSENT:

By signing this consent form, you agree that you understand the procedures and any risks and benefits involved in this research. You also agree that you are legally able to provide consent for your participation in this study. ***You are free to refuse to participate or to withdraw your consent to participate in this research at any time without penalty or prejudice; your participation is entirely voluntary.*** Your privacy will be protected because you will not be identified by name as a participant in this project.

The University of North Carolina at Greensboro Institutional Review Board, which ensures that research involving people follows federal regulations, has approved the research and this consent form. Questions regarding your rights as a participant in this project can be answered by calling Mr. Eric Allen at (xxx) xxx-xxxx. Questions regarding the research itself will be answered by Brandi McCullough by calling (xxx) xxx-xxxx, or Rebecca Adams by calling (xxx) xxx-xxxx.

By signing this form, you are agreeing to participate in the project described to you by Brandi McCullough.

Participant's Signature*

Date

Capacity to Sign Consent (CSC) Measure

1. What are we going to do today?
2. Why did I choose you for this interview?
3. How long will this interview take?
4. What is expected from you today?
5. What do you do if you do not wish to continue?

Adequate answers given by the participant that demonstrate her ability to understand the key points of the study:

1. We are going to have an interview. We are going to talk about my disease. We are going to talk about my friendships.
2. I was chosen for this study because I have dementia and/or Alzheimer's disease.
3. This interview will take between one and two hours.
4. I am expected to answer questions. I am expected to talk about my disease and my friendships.
5. If I do not wish to continue, I will tell the interviewer and ask to stop.

Interview Guide for the Person with dementia and/or Alzheimer's (PWD/PWA)

- I. Respondent's demographic variables
 - a. Age (When were you born?)
 - b. Educational history (How much schooling did you have?)
 - c. Occupational history (What did you do for a living?)
 - d. Geographic mobility history (Are you from here?)
 - e. Marital history (Were you married?)
 - f. Religious preference (What religion are you?)
- II. Global Friendship Patterns of PWD/PWA
 - i. How important are friends to you? Do you have many friends or do you tend to keep to yourself? Was it always like this?
 - 1. *Probe:* Are you interested in making new friends? Why or why not? Would you like to continue the friendships you had before?
- III. Experience of Dementia/Alzheimer's Disease
 - a. Diagnosis of Dementia/Alzheimer's disease
 - i. Can you tell me the story of how you were diagnosed? When did it happen? What led up to it?
 - b. Tell about your experience of the disease.
 - i. What is it like to have Dementia/Alzheimer's disease?
 - ii. Has your life changed since you were diagnosed with this illness? If so, how?
- IV. Mixed Friendship Under Study
 - a. Identify one person you would consider to be a good friend. Are you still friends with this person? If not, why not? Does s/he have dementia too? Is s/he related to you? (If so, ask participant to identify another friend.) Why do you consider this person a good friend? Does s/he know you have Dementia/Alzheimer's disease? How did s/he find out? Why/why not did you tell him/her? Can you talk about your disease with your friend?
 - b. Friend's demographic variables
 - i. Age (How old is your friend?)
 - ii. Educational history (How much schooling did your friend have?)
 - iii. Occupational history (What did your friend do for a living?)
 - iv. Geographic mobility history (Is your friend from here?)
 - v. Marital history (Was your friend married?)
 - vi. Religious preference (What religion is your friend?)
 - vii. Race (What color is your friend?)
 - c. Friendship initiation
 - i. Take me back to when you became friends. How old were you? Where did you meet? Why did you become friends?

d. Friendship processes & structures

i. Processes

1. (Affective) How do you feel about each other? Was it always this way?
 - a. Does s/he make you feel good or bad about yourself? Why?
 - b. *Probe:* Are you comfortable around your friend? Can you be yourself around your friend? Was it always this way? Are you comfortable enough with your friend to talk about your disease?
2. (Behavioral) What kinds of things do you and your friend do together? What kinds of things do you do for each other? How often? Was it always like this?
 - a. *Probe:* Do you cook each other meals? Do you offer each other a ride? Do you give each other advice? Anything else?
 - b. Do you rely on each other much? Is the give and take equal? Was it always this way?
 - c. Does s/he ever ask you to do things you can't do? Does s/he ever kind of take over for you when you don't need her to? Did s/he always do this?
3. (Cognitive) What do you think of your friend? Did you always think of her this way? What might your friend think of you? Was this always the case?
 - a. *Probe:* Has s/he ever acted like your disease was a problem? Does s/he ever talk to you about your disease? When you're with him/her, is it easy to forget that you have Dementia/Alzheimer's disease? Why?

ii. Structures

1. (Solidarity) Are you pretty close with him/her? Was it always this way? What made you two so close?
 - a. Is s/he understanding of you? Can you talk with him/her openly about things?
 - b. Could you imagine your life without him/her?
 - c. Does being his/her friend make your life easier or harder?
2. (Power) Who is the decision maker in your friendship? Was it always this way? Eating out, making plans, etc. If you were to disagree with each other, who would get their way?
3. (Status) Does s/he act like s/he respects you? Do you have respect for him/her? Was it always this way?

e. Friendship phases

- i. (Maintenance) Are you in touch with your friend enough? Would you prefer to have more frequent contact, or do you want less frequent contact?
- ii. How often are you in contact? Was it always this frequent? Who usually calls or makes the contact?
 - 1. Is your relationship any different than it used to be? Is it any stronger or weaker?
- iii. If friendship is still active: Why do you think your friendship has lasted? Do you think your friendship will ever end for any reason?

V. General Questions

- a. What makes you a good friend? Is there anything that makes you not such a good friend?
- b. Do you think your illness has affected your friendship?
- c. Have you made any new friends since you have been diagnosed with Dementia/Alzheimer's disease? How did you meet them, and why did they become your friend?
 - i. Would you like to make new friends? Do you have the chance to make new friends? Is it easy or hard for you to make new friends? If so, why?
- d. What kind of advice would you give to a person who has a friend with Dementia/Alzheimer's disease? What kind of advice would you give to a person with Dementia/Alzheimer's disease about friendships?
- e. Are there any questions I should have asked, but I didn't?
- f. If your friend was here right now, and you could tell him/her anything, what would it be?
- g. What do you want others to know about what it is like to have Dementia/Alzheimer's disease?

APPENDIX B: TEXT CODES

List of Text Codes

(STIGMA) Stigma: the negative reaction of the friend toward the PWA as a result of feelings of discomfort or shame related to the disease as experienced by the PWA and/or the friend, often resulting in the dissolution of the friendship.

(LSTIGM) Lack of stigma: the absence of negative reactions of the friend toward the PWA; the absence of shame or discomfort related to the disease as experienced by the PWA and/or the friend.

(EXCDIS) Excess disability: disability that is experienced by the PWA caused by the treatment of the friend, having nothing to do with the biological progression of the illness. This happens when the friend takes on more responsibility than necessary, often accompanied by a well-meaning paternalistic attitude, resulting in a loss of autonomy for the PWA.

(LEXCDI) Lack of excess disability: the absence of a social disability for the PWA caused by the friend; when the PWA is empowered by the friend, and is still able to retain a sense of autonomy.

(PTPMEN) Person-turned-patient mentality: the perspective of the friend that frames the PWA primarily in terms of the illness.

(LPTPME) Lack of the person-turned-patient mentality: the perspective of the PWA's friend that allows him or her to not think of the PWA primarily in terms of her disease.

(INEQSE) Inequitable social exchange: the PWA's increased dependency on the cognitively intact friend, resulting in an unequal amount of "give" and "take."

(EQUISE) Equitable social exchange: a balanced dependency between the PWA and her friend, resulting in a relatively equal amount of "give" and "take."

(FRFEAR) Fear: experienced by the cognitively intact friend of his or her own mortality as a result of being in contact with the PWA.

(LFRFEA) Lack of fear: when the PWA's friend does not experience fear of his or her own mortality as a result of being in contact with the PWA.

(COMCHA) Communication challenges: difficulties in communication that the PWA might have with her friend, such as remembering names, the inability to articulate thoughts, difficulty following a conversation, etc.

(LCOMCH) Lack of communication challenges: the absence of difficulties in communication between the PWA and her friend.

(OPDIAL) Open dialogue: for the PWA, the freedom to openly discuss her experience of the disease with her friend, involving the comfortability of disclosing her diagnosis.

(CLDIAL) Closed dialogue: for the PWA, the inability to freely discuss her experience of the disease with her friend, involving being uncomfortable while disclosing her diagnosis, or unable to do so altogether.

(ROLERE) Redefinition of roles: both the PWA and the friend having to adapt to the effects of the disease and the various recasting of normative friendship responsibilities.

(ROLECO) Continuity of roles: when the PWA and her friend do not have to adapt to the effects of AD and the lack of having to recast normative friendship responsibilities; the ability of the dyad to maintain the same roles held prior to the PWA's development of the disease.

(SHEXPE) Shared experience: the ability for the PWA and the friend to offer each other a source of mutual understanding.

(LSHEXP) Lack of shared experience: the inability for the PWA and the friend to offer each other a source of mutual understanding.

(HOMOPH) Friendship homophily: is experienced when the PWA and the cognitively intact friend are able to share the same cognitive or social functioning capacities.

(LHOMOP) Lack of friendship homophily: is experienced when the PWA and the cognitively intact friend no longer share the same cognitive or social functioning capacities.

(NETBRE) Network breakdown/isolation: the process by which the friendships of the PWA begin to deteriorate and eventually disappear altogether.

(NETRET) Network retention/social engagement: the lack of the deterioration of the friendship networks of the PWA; when the PWA is able to maintain friendships post-AD development.

(SOLIDA) Solidarity: the closeness experienced between the PWA and the cognitively intact friend.

(LSOLID) Lack of solidarity: an absence of closeness experienced between the PWA and the cognitively intact friend.

(DESENG) Desire to stay engaged/maintain friendships: the PWA's resistance to disengagement by the continued effort to remain connected with others by remembering names, things significant to the friendship, etc.

(DESDIS) Desire to disengage/dissolve friendships: the PWA's desire to discontinue the friendship(s) held prior to her development of AD.

(REVSOP) Realism vs. optimism: between the PWA and her friend, the balance between remaining positive about the experience of the disease and maintaining a realistic attitude about living with the effects of a degenerative disease.

(LREVSO) Lack of realism vs. optimism: between the PWA and her friend, an imbalance between remaining positive about the experience of the disease and maintaining a realistic attitude about living with the effects of the disease; either being "too" negative or "too" positive.

(GROWTH) Growth: the possibility for the friendship of the PWA and her friend to experience a heightened closeness that is positive in nature, increased affective qualities, greater self-disclosure, stronger ties, etc.

(LGROWT) Lack of growth: the absence of heightened closeness, affective qualities, self-disclosure, and stronger ties for the friendship of the PWA and her friend; the increased vulnerability of the friendship to dissolve.

(NEWFRI) New friendships post-AD development: the chance for the PWA to engage in new friendships after developing AD.

(LNEWFR) Lack of new-friendships post-AD development: the lack of a chance for the PWA to engage in new friendships after developing AD.

(WELLBE) Well-being: the state of being happy and/or healthy; when the PWA has a good quality of life.

(ILLBEI) Ill-being: the state of being unhappy and/or unhealthy; when the PWA has a bad quality of life.

(SELFES) Self-esteem: a confidence and satisfaction with oneself; when the PWA feels good about herself.

(LSELF) Lack of self-esteem: being unconfident and dissatisfied with oneself; when the PWA feels bad about herself.

(SELFHO) Selfhood: the PWA's sense of individuality, or sense of identity.

(LOSELF) Loss of self: when the PWA is unable to feel human, or like herself; a loss of identity.

(POWER) Power: the PWA's ability to exert her influence over her friend; her ability to control a situation within the relationship.

(LPOWER) Powerlessness: the PWA's inability to exert her influence over her friend; her inability to control a situation within the relationship.

(STATUS) Status: the level of respect the PWA receives from her friend; when she is regarded highly by her friend.

(LSTATU) Lack of status: occurs when the PWA receives little to no respect from her friend and/or is disregarded as unimportant.

(FRECON) Frequent contact: when the PWA has a regular amount of interactions with her friend; once per week or more.

(INFRCO) Infrequent contact: when the PWA has an irregular amount of interactions with her friend; once per month or less.

(HIIMFR) High importance of friend: when the PWA places a high level of priority on her friendship.

(LOIMFR) Low importance of friend: when the PWA places a low level of priority on her friendship.

(COMFRI) Being comfortable with friend: a high level of comfort and ease as experienced by the PWA when interacting with her friend.

(UNCOMF) Being uncomfortable with friend: a low level of comfort and ease as experienced by the PWA when interacting with her friend.

(TRANSP) Transparency/vulnerability: the ability to be open and honest for the PWA with her friend.

(GUARDE) Guardedness: when the PWA does not have the ability to be open and honest with her friend.

(HISOSU) Heightened social support: an increase in the various types of aid offered to the PWA by her friend.

(LOSOSU) Lowered social support: a decrease in the various types of aid offered to the PWA by her friend.

(HOMOGE) Homogeneity: similarities in demographic characteristics, attitudes, values, and beliefs between the PWA and her friend.

(HETERO) Heterogeneity: differences in demographic characteristics, attitudes, values, and beliefs between the PWA and her friend.

(GOSEFR) Good sentiments toward friend: an overall good feeling the PWA has regarding her friend.

(BASEFR) Bad sentiments toward friend: an overall bad feeling the PWA has regarding her friend.

(FRFACI) Friendship facilitators: any quality, characteristic, or situation that has helped the PWA form and maintain her friendship.

(FRPREV) Friendship preventors: any quality, characteristic, or situation that has prevented the PWA from forming and maintaining her friendship.

(POFREF) Positive friendship effects: the favorable results AD has had on the friendship of the PWA.

(NEFREF) Negative friendship effects: the unfavorable results AD has had on the friendship of the PWA.

(ADVPWA) Advice to other PWAs: recommendations from the PWA to other PWAs regarding friendships and being a friend.

(ADVFRP) Advice to friends of PWAs: recommendations from the PWA to friends of PWAs regarding friendships and being a friend.